



GÖTEBORGS UNIVERSITET

Department of Social Work

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# **From boom to bust: how the economic crisis renders disabled people to the bottom shelf**

A qualitative study of the views of adults with physical impairments on the economic crisis in Co. Kerry, Ireland

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# Abstract

The aim of this study is to explore the impact of the economic crisis and governmental expenditures on adults with physical impairments in Co. Kerry, Ireland. Closer examination of the governmental spending on services for adults with physical impairments and cutbacks in the distribution of benefits, allowances and grants and its effects on living conditions will be investigated. Personal views and opinions of adults with physical impairments on the impact of the crisis in terms of their autonomy/independence and the rights based approach will be also examined to answer the research question. Semi structured, qualitative interviews were conducted with ten participants to collect the research data. To analyze the data, the thematic analysis method was employed with the help of the theoretical framework of social model of disability and the rights based approach. These theoretical perspectives give a critical overview of understanding of disability and emphasize the importance of focusing on rights rather than needs in approach to disability. The findings of this study demonstrate that the economic crisis and governmental expenditures impact on adults with physical impairments standard of living, health and wellbeing and access to services. The findings also show that as a result their autonomy has been under threat due to growing dependency and rising decline in choice and control adults with physical impairments have over their lives.

**Title:** From boom to bust: how the economic crisis renders disabled people to the bottom shelf. A qualitative study of the views of adults with physical impairments on the economic crisis in Co. Kerry, Ireland.

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**Key words:** adults with physical impairments, disabled people, disability, economic crisis, austerity measures, social model, rights based approach, Ireland, Co. Kerry

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## List of abbreviations

BD	Business Dictionary
CDO	Cambridge Dictionary Online
EFC	European Foundation Centre
ESRI	Economic and Social Research Institute
EU	European Union
FAS	Irish National Training and Employment Authority
GP	General Practitioner
HSE	Health Service Executive
ICFDH	International Classification of Functioning, Disability and Health
IWA	Irish Wheelchair Association
NDA	National Disability Authority
NESDO	National Economic and Social Development Office
NGO	Non Governmental Organisations
OT	Occupational Therapist
RBA	Rights Based Approach
UN	United Nations
UNFPA	United Nations Population Fund
UPIAS	Union of the Physically Impaired Against Segregation
VAT	Value Added Tax
VHI	Voluntary Health Insurance
WHO	World Health Organisation

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# 1. Introduction

This research will investigate the impact of the recent economic crisis and governmental expenditures on adults with physical impairments caused by conditions such as multiple sclerosis, stroke and spinal cord injuries in Ireland, county Kerry. In Ireland, it took many years of campaigning, protesting and fighting in order to influence the policy makers and finally introduce legislation inclusive of disabled people and to establish services and relevant legislation that would secure their status. In the past, in Ireland the church, religious organisation and family members were the main providers of care. However, in the second half of the 20<sup>th</sup> century the society and its attitudes were changing due to joining the United Nations in 1955 and the European Union in 1973. Ireland became more respectful and considerate of human rights what resulted in changing methods of the delivery of social and welfare provisions. Traditional, charitable and institutionalized ways of care and treatment were slowly replaced by public, private and nongovernmental organisations.

Ireland entered the 21<sup>st</sup> century with a promptly growing economy which resulted in the strengthening of the position and rights of the vulnerable, amongst them, disabled people. Disabled people were experiencing more inclusion, equality and participation in all areas of life with the principle of *Nothing about Us without Us*<sup>1</sup>. Government policies in education, employment, housing, healthcare, welfare and social services provision were becoming more inclusive of disabled people giving them more freedom, more opportunities and more prospects to live relatively normal lives. The economic boom, known as the *Celtic Tiger* vastly contributed towards the inclusion of disabled people. Ireland as an economically prosperous country started moving away from charitable, institutionalised approach to disability, in the direction of a more person centred, community based and inclusive attitude with respect to disabled people.

Nevertheless, the prosperity of the *Celtic Tiger* came to an end around 2008. The economy started rapidly slowing down which brought about drastic changes in public expenditures in healthcare, social and welfare provision. Most vulnerable citizens, among them disabled people, have since been affected with cut backs that have an immense effect on their lives and shape how they ought to live. Since, the motto *Nothing about Us without Us* seems to have lost its importance in the bigger picture of trying to make savings in public spending in order to save the Irish economy. Since the onset of the economic crisis cuts and reductions in home supports, income, healthcare and treatment have been felt by many of those who have disabilities. Also changes in public opinion towards disabled people have been changing towards more negative one.

This research will investigate the impact of the economic crisis and governmental expenditures on adults with physical impairments in Co. Kerry, Ireland. The rationale behind a choice of this topic lies behind my experiences of working with adults with physical impairments in Kerry between 2008 and 2012. As I entered this employment while there was still ample amount of funding flowing towards the disability sector, I was able to observe how changes were coming about hastily. This enlightened my understanding how quickly the life of an adult with physical impairment can change and how they need to find their feet in this new, unfavourable situation. The reasoning behind this research and why it is needed will be further clarified in more detail in the Background section under the Research Aims and

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<sup>1</sup> The term “Nothing About Us Without Us” is based on “principle of participation and it has been used by Disabled Peoples Organizations throughout the years as part of the global movement to achieve the full participation and equalization of opportunities for, by and with persons with disabilities.” (UN Enable 2014)

Questions. This study does not aim to explain how the economic crisis and governmental expenditures affect all disabled people in Ireland, but to give an overview how it impacts on adults with physical impairments in county Kerry.

## **2. Relevance to social work and human rights**

There is an undeniable relationship between social work, human rights and disability issues. Social workers promote social change, empowerment and problem solving in human relationships (Oliver, Sapey and Thomas 2012) and work with individuals and groups that are marginalised. Recession generated new concerns for social workers as the economic crisis and governmental fiscal policies deeply affect disabled people and have a deteriorating impact on them. The role of a social worker in times of the crisis is to facilitate support for disabled people but also provide important messages to government and those responsible for social policy and political outcomes that is evidence based (Truell 2014). The economic crisis creates new challenges for social workers in terms of social and economic justice as there is a growing inequality amongst marginalised people in terms of income, prosperity and allocation of resources (Polack 2004). As emphasized by Goldberg (2012), the economic crisis has damaging effects on social workers clients because of the changes in political beliefs, the market economy and governmental policies. Therefore, social work profession can be a crucial factor in working against devastating economic, social and political inequalities. The crisis increases social exclusion, social isolation, deprivation as well as oppression and growing dependency (Strier 2013). The effects and outcomes of the economic crisis and governmental expenditures create more challenges for social workers as there is a growing increase of caseloads involving disabled people. Social workers have a responsibility in times of crisis to promote even more disability awareness, advocate for disabled people and stress the significance of “much more engaged, egalitarian, social rights-based and reflexive social work practice” (Ibid p.351). In the current economic climate social workers have even more obligations to assist disabled people in sourcing the individual, community, social and economic resources to facilitate them to achieve the full potential in their lives (Oliver, Sapey and Thomas 2012).

Disabled people have human rights like everyone else and encounter many difficulties in terms of human rights and equality problems (Centre on Human Rights for Disabled People 2007). Holland (2012) argues that in times of crisis social spending should be under protection in order to fulfil citizens’ human rights. Since the onset of the economic crisis disabled people face explicit issues in relation to their human rights. The access to for instance social protection or health during recession times has got worse, preventing disabled people from inclusion and full and equal citizenship. Austerity measures can have potentially dangerous effects on recognition of the rights of disabled people. Tight governmental public spending brings under threat, the rights of marginalised citizens leaving them isolated, depriving them of autonomy, independence and undermining their self-determination. The Irish governments’ health and social care policies are based on the rights based approach that utilizes the standards of human rights to direct practice, policy and the delivery of service (Ibid). Therefore, changes in policies and practice in relation to disabled people that are unfavourable to them, create exclusion, inequality and undermine their human rights and become a human rights issue. The rights based approach and social model of disability should be at the heart of present and future government proceedings.



## 3. Background

### 3.1. Terminology

In this section the use of terms frequently used in this paper such as disability, impairment, economic crisis and austerity measures will be explained.

#### 3.1.1. Disability and impairment

There have been many key amendments in the way we define disability. The term disability has several meanings depending on the circumstances within which it is used. Therefore, we should remain cautious when choosing a definition. The medical model of disability shaped the manner in which disability used to be defined; however there has been a significant move towards the social model since it evolved in the second half of the 20<sup>th</sup> century.<sup>2</sup>

The Irish Disability Act (2005) defines disability as “disability, in relation to a person, means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment”. Persons who participated in this study have physical impairments such as permanent limitations and lack of movement in one or both lower and upper limbs that were caused by conditions such as multiple sclerosis, stroke and spinal cord injuries.

As highlighted by Oliver and Barnes (2012), definitions of *disability* and *impairment* have been argued since the 1960's and there are major differences in usage of both terms. This generates various debates and over the years there have been many redefinitions of disability. Nevertheless, those two terms were distinguished for the first time in 1976 by UPIAS and stated

- *Impairment* ‘lacking part of all of a limb, or having a defective limb, organ or mechanism of the body’
- *Disability* ‘the disadvantage or restriction of activity caused by contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities’ (UPIAS 1976, p. 14)

Furthermore, the International Classification of Functioning, Disability and Health explains variations in terms of *disability* and *impairment* as follows

*Disability* is an umbrella term for impairments, activity limitations and participation restrictions. It denotes the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors). [...] *Impairment* is a loss or abnormality in body structure or physiological function (including mental functions). Abnormality here is used strictly to refer to a significant variation from established statistical norms (i.e. as a deviation from a population mean within measured standard norms) and should be used only in this sense. (WHO 2001, p. 213)

For the purpose of this discourse, it has been chosen to refer to participants of this study as *adults with physical impairments*. Moreover, term *disabled people* will be used in this text when appropriate. It is important to highlight that Oliver et al. (2012) choose to use the term

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<sup>2</sup> Medical/individual and social models of disability will be discussed in separate chapter.

*disabled people* rather than *people with disabilities* because “to accept the label *people with disabilities* is to accept that disability is an individual rather than social problem [...] and *disability* is a social creation” (p. 6). There have been many debates as to what is appropriate way of reference to those who have disability. Mike Oliver is an advocate and activist of disability movement. He also has a disability himself and uses wheelchair. He is a pioneer in a disability research and published many books in relation to this topic over the years. Therefore, one would deem, using the term *disabled people* seems appropriate following Oliver’s remarks. It is imperative to stress divergence of the use of terms of *disability* and *impairment* to avoid condemnation, perplexity and debate among potential readers.

### 3.1.2. Economic Crisis and Austerity Measures

In line with the Business Dictionary (BD) economic crisis is

A situation in which the economy of a country experiences a sudden downturn brought on by a financial crisis. An economy facing an economic crisis will more likely experience a falling GDP<sup>3</sup> a drying up of liquidity<sup>4</sup> and rising/falling prices due to inflation/deflation<sup>5</sup>. An economic crisis can take a form of a recession<sup>6</sup> or a depression<sup>7</sup> (BD 2013).

Furthermore, as many terms in reference to governmental cut backs and expenditures will be made in this thesis, it is of importance to clarify what austerity measures are. According to the Cambridge Dictionaries Online (CDO), austerity measures means “official action by a government to reduce the amount of money it spends, or the amount of money that people in a country spend” (CDO 2013). Basically, austerity measures target country’s fiscal policies and target inflation so as to reduce government’s budget deficit. Austerity measures aim at generating more money from for instance increase of income tax or VAT<sup>8</sup> and rising prices in order to reduce and repay debts. Austerity measures are related to slow economic growth and rising unemployment (Economic Help 2013).

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<sup>3</sup> Gross Domestic Product

<sup>4</sup> “The degree to which an asset or security can be bought or sold in the market without affecting the asset's price. Liquidity is characterized by a high level of trading activity. Assets that can be easily bought or sold are known as liquid assets”. (Investopedia 2013)

<sup>5</sup> *Inflation*: The rate at which the general level of prices for goods and services is rising, and, subsequently, purchasing power is falling. Central banks attempt to stop severe inflation, along with severe deflation, in an attempt to keep the excessive growth of prices to a minimum.” (Investopedia 2013). *Deflation*: “A general decline in prices, often caused by a reduction in the supply of money or credit. Deflation can be caused also by a decrease in government, personal or investment spending. The opposite of inflation, deflation has the side effect of increased unemployment since there is a lower level of demand in the economy, which can lead to an economic depression. Central banks attempt to stop severe deflation, along with severe inflation, in an attempt to keep the excessive drop in prices to a minimum” (Investopedia 2013)

<sup>6</sup> “A significant decline in activity across the economy, lasting longer than a few months. It is visible in industrial production, employment, real income and wholesale-retail trade. The technical indicator of a recession is two consecutive quarters of negative economic growth as measured by a country's gross domestic product (GDP)” (Investopedia 2013)

<sup>7</sup> “A severe and prolonged downturn in economic activity. In economics, a depression is commonly defined as an extreme recession that lasts two or more years. A depression is characterized by economic factors such as substantial increases in unemployment, a drop in available credit, diminishing output, bankruptcies and sovereign debt defaults, reduced trade and commerce, and sustained volatility in currency values. In times of depression, consumer confidence and investments decrease, causing the economy to shut down.” (Investopedia 2013).

<sup>8</sup> Value Added Tax

### 3.2. Problem area and facts

According to the Census 2011<sup>9</sup> there are 595,355 disabled people living in the Republic of Ireland (Central Statistics Office 2012). This means that total of 13% of the Irish population has some form of disability (Disability Federation of Ireland 2014). Ireland has a mixed economy of welfare; therefore the state takes certain responsibility for citizens in times of need in terms of provision of social welfare payments and support provision<sup>10</sup> (Good 2003, Nolan 2003, Citizens Information 2014). Services and supports to disabled people are provided by mix of public/state, NGO and private provisions (Good 2003). Disabled people in Ireland are entitled to invalidity pension or disability allowance as a form of income support. The former is paid to those who are permanently unfit to work and is of higher rate and the latter is means tested and applies to people who are affected with illness or certain impairment that restricts their capacity to work (McManus 2003, Department of Social Protection 2014). Additionally, disabled people are eligible for the housing adaptation grants, mobility aids grants, medical cards<sup>11</sup> and any other social support that is available to people on low income or unemployed. Disability results in many extra costs such as additional heating, care and assistance, mobility and communication aids that main social welfare payments do not take into account (McManus 2003).

Since 1998 there have been significant developments in disability policy and the lives of disabled people were improving (Quin and Redmond 2003). The Commission on the Status of People with Disabilities was established in 1996 aiming at observing lives of disabled people in contemporary Ireland (National Disability Authority 2009). Formation of the Commission was a milestone in both process and outcome (Conroy 2010). The Commission argued that disabled people have a basic and fundamental right to equitable, person centred and accessible health care, access to information in regard to services and entitlements, adequate transport facilities, right to an early assessment and rehabilitation and to community support (Ibid). The Commission's contribution to improvement of lives of disabled people was vast. Consequently, in 2000 the National Disability Authority was founded. The Authority has the advisory function to the government and operates as an independent organisation. The NDA, through its work and research has been an important factor in moving towards the framework of social model of disability in Ireland, influencing Irish disability policies and stressing the elimination of barriers to attain full citizenship of disabled people (McManus 2003, NDA 2009).

Spending on social services has been growing in Ireland since the 1960's and issues such as mainstreaming of public services, socio-economic rights, for instance the right to education, healthcare or housing emerged (Coughlan 1984, McManus 2003, Schafer 2009). As a result of changes in approach to disability and the establishment of the above mentioned bodies, the Irish government put in place legislation that safeguards and strengthens position of vulnerable citizens. The Equal Status Acts 2000 and 2004 (Government of Ireland 2000 and 2004) opened doors to mainstreaming of services for disabled people and ensured that their needs and requirements have to be accommodated and taken into account. Moving forward, the Irish government reaffirmed the rights of disabled people in 2005 with launching the Disability Act (Government of Ireland 2005). The primary purpose of this legislation was to enhance and press forward involvement of disabled people in ordinary, everyday life by improving assessment of needs and rehabilitation, accessibility of support and services and universal access. Establishment of new legislation that protects disabled people was an

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<sup>9</sup> Irish population survey

<sup>10</sup> This is subject to means testing or/and specific criteria fulfilment

<sup>11</sup> These allow free access to healthcare and medication

indispensable condition to *turning ability/disability* problems and dialog away from the previous *sacrificial frugalism* in the direction of a more reassuring and legislative future (Conroy 2010).

Continued strengthening of the position and rights of disabled people in Irish society, the government introduced the National Disability Strategy in 2004 and in 2006 set out the social partnership agreement known as *Towards 2016*. The strategy's goal is the mainstreaming of lives of disabled people and prohibition of any form of discrimination against them. *Towards 2016* agreement outlines the agenda how social and economic needs of vulnerable groups shall be met (e.g. reasonable income, access to healthcare services and medication, universal access, independent living) throughout different life stages, one of those groups are disabled people. Ireland has also signed, however did not ratify, the United Nations Convention on the Rights of People with Disabilities (2006). The Irish legislation does not fulfil the criteria for ratification as it lacks the mental capacity legislation (Citizens Information Board 2012, Inclusion Ireland 2012). It is estimated that the Irish government is going to reinforce the mental capacity law within the coming year and should ratify the convention shortly.

From the late 1990's to early 2000's the Irish economy was successfully and rapidly growing, attracting foreign investments, the construction sector was booming, new employment opportunities were emerging and Ireland experienced growth in inward migration (Schafer 2009, Conroy 2010, Holland 2012). Ireland went through transition from one of the poorest economies in Europe towards one of most prosperous. The property market was booming, housing prices were moving beyond the affordability of average citizens and eventually borrowing went out of control. The mixture of a housing bubble, careless banking practices, regulatory failures and deficits in governance merged and strived to drive the economy into financial abyss (Holland 2012). Ultimately, the recession created a lot of tension in welfare provision and changed the amount of money spent and the way social services are distributed and Ireland started to struggle to maintain previous standards in welfare provision (Conroy 2010).

Since the beginning of the economic crisis income support and other benefits have been cut with distressful effects on disabled people, rising levels of inequality and poverty (Holland 2012, Irish Wheelchair Association 2012). Funding and support which allows disabled people to live independently and regain respect and dignity has been reduced and/or slowly withdrawn. Financial recovery policies introduced by the Irish government due to the crisis have been of strikingly retrogressive character and jeopardize reforms and developments that have been done over the years (Holland 2012). Ireland started to lose its sovereignty and economic pressures affected the lives of disabled people to slip further behind, what is mostly apparent in individual social supports and participation in life (Disability Federation of Ireland 2012). Since 2008 every yearly budget has been targeting disabled people with stringent cuts that cause additional hardships. The economic crisis caused public and voluntary sectors to change their working practices and prioritise delivery of services and supports. In view of the fact, that since commencement of the recession, economic recovery have been prioritised over social inclusion and participation, outcomes for disabled people and risk of poverty and exclusion has risen among this group. Reductions have been made in the HSE<sup>12</sup> funding for disability services; cuts to the housing adaptation grant, mobility allowance, and motorised transport grant as well as cuts in number of personal assistance and home help hours targeted human rights, social inclusion and participation of disabled people (Disability Federation of Ireland 2012).

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<sup>12</sup> Health Service Executive is responsible in Ireland for the provision of public health services

### 3.3. Research aims and questions

The aim of this study is to explore the impact of the economic crisis and governmental expenditures on adults with physical impairments. The study has been carried out in Co. Kerry, Ireland. I have chosen to delve into and discuss this topic hoping that understanding the scale of the problem will highlight the hindrance of the public spending cuts on the everyday life of an adult with physical impairment. I have decided to focus on the area of county Kerry as I believe the scale of this research would not allow me to collect enough of pertinent data throughout Ireland. I have chosen to interview adults with physical impairments and not social workers or other professionals who deal with them, in order to provide the most reliable information that comes directly from adults with physical impairments and is not modified in any way. Consequently, the decision to interview only adults was made after initial enquires with social workers about obtaining access to children with physical impairments. I was advised that trying to explore the situation of children with physical impairments would bring about access issues as Ireland has strong child protection and confidentiality policies. This would mean that probably, I would have to interview parents, legal guardians or social workers and as my intention is to look at the problem from a person's with physical impairment perspective, this was not feasible. The same would apply, if I had tried to gain access to both adults and children with intellectual impairments. The questions were built upon the strong interest I have developed in this topic while working with adults with physical impairments in times of economic crisis. This research has the potential to contribute towards further research in social work, human rights or any other related discipline, on the position of adults with physical impairments in times of financial crisis as well as to explore areas most affected by the recession that are of interest to adults with physical impairments.

In order to highlight whether the economic crisis has had an influence on everyday lives and living conditions of adults with physical impairments, it will be explored as to how governmental public spending decisions correspond with the ethos that lies behind social model of disability. Accordingly, adults with physical impairments perception of the economic crisis in terms of their autonomy/independence will be explored by looking at how it relates to the rights based approach.

The main research question guiding this study is:

How the economic crisis and governmental expenditures impact on adults with physical impairments in Co. Kerry, Ireland?

The main research question will be further explored by trying to answer the following questions:

1. How reductions in governmental spending on services for adults with physical impairments and cutbacks in the distribution of benefits, allowances and grants affect their lives and living conditions?
2. How adults with physical impairments perceive cuts in benefits, services and supports in terms of their autonomy/independence and the rights based perspective?

## 4. Literature review

The literature review gives an overview of the existing evidence of the impact of the economic crisis and austerity measures on disabled people. There has been a lot of evidence based research carried out around the world ongoing since the global economic crisis began in 2008 and I have attempted to refer to the most recent literature available on this subject. Most research seems to be undertaken by the EU states which have been mostly affected by the economic crisis. I have researched both the literature available from Ireland as well as from other EU countries. The themes researched included the economic crisis, Ireland, people with physical impairments, disabled people, vulnerable groups and human rights. Academic journal articles, Irish and UK governments' publications, European Union reports and online-documents have been employed to discuss the effects of the economic crisis on disabled people. During the literature review search, it became apparent that because the subject is quite recent, limited scholarly articles are available on this topic.

### 4.1. Research from Ireland

According to research the majority of the Irish people have been economically struggling since the beginning of the crisis in 2008, with government budget deficits affecting vulnerable people on the lowest income (Whelan and Maitre 2010, McKeogh 2012, NESDO 2013). Whelan et al. (2010) argue that vulnerability, poverty and dependence on welfare provisions are strongly correlated especially in times of the economic crisis. The NESDO (2013) study has categorized groups according to vulnerability with people who are ill or disabled counting for the 7 % of the group that has been classified as *poor and vulnerable*. Financial changes in income tax, social welfare payments, VAT and allowances made by the Irish government between 2009 and 2012 have been progressive and detrimental to vulnerable citizens (NESDO 2013). The report highlights certain areas that have been of particular concern. It has been recognized that the *poor and vulnerable* that are at the highest risk of poverty have experienced rising levels of indebtedness, which is a result of a permanent shortage of money. Furthermore, decrease in public expenditure on welfare, supports and service provision, decline in the HSE spending on areas such as primary care, the medical card scheme and clinical spending worsen their situation (Ibid). Retrogressive measures and cuts have been introduced in all areas of public spending not omitting welfare sector and social protection while at the same time demand for these services has been on the rise owing to the economic crisis. The effects of reductions in governmental expenditures result in vulnerable citizens remaining poor or become even poorer (Ibid).

Moreover, in accordance with research carried out by McKeogh (2012) economic crisis have had serious impact on the lives of disabled people increasing poverty levels and inequality amongst them. The study has highlighted that disabled people are most vulnerable to poverty. Since 2009 the government introduced severe reductions in welfare benefits for disabled people by cutting disability allowance from €204.30 to €188 per week, the disablement pension from €235.40 to €226 per week, the carer's allowance from €220.50 to €212 per week and the carer's benefit from €220 to €212 per week which seriously impacted the income of disabled people and the capacity of relatives to provide support for disabled family members (Ibid). The agencies and services users interviewed for this study claimed that waiting lists for many services including access to hospital care have increased, assessment for support services and personal assistance services became more rigorous and eligibility criteria changed (Ibid). The research shows that 4 out of 10 disabled people have been subjected to deprivation by 42% in 2009 and 2010 placing them in negative equity (Ibid).



Government's cutbacks have led to agencies that provide services for disabled people, such as the HSE, to reduce working hours, limiting availability of necessary training to staff and cuts in personal assistance and home help hours that influenced the quality and accessibility of supports (Ibid). Furthermore, the research pointed out that reductions in governmental spending in the disability sector resulted in the closure of many services and pushed many disabled people to pay a greater amount for services. The findings showed that a more medical, professionalised model has been adapted in the provision of services, independent living less prioritised, privatization of many social services and use for profit organization became more common ( Hauben et al. 2012, McKeogh 2012). The study demonstrated that deductions, delay and withdrawal of benefits led to insecurity in disabled people's lives while additional charges that have been introduced as a consequence of the economic crisis, such as property tax or water charges, add to their impoverishment (McKeogh 2012).

## **4.2. Research from EU countries**

Lambert (2013) claims that across the EU disabled people are being unevenly touched by public expenditure and as a consequence are deprived of support services that enable them to be part of their communities and live independent lives. Savage cuts in service and support provisions and benefits have been affecting disabled people directly and have negative impact on their lives and work against the empowerment and promotion of the social model of disability in the EU countries (Ibid). Moreover, Hanan (2012) maintains that the economic crisis has many social consequences on all citizens and that austerity measures intensify poverty and inequality among vulnerable groups being hit hardest. Links are made between austerity measures and worsening effects of long-term chronic illness and disability that is of anxiety to disabled people and their families (Evans 2011, Hanan 2012) The measures also drive disabled people into debt and worsen their living conditions and contributed to the redesign of eligibility criteria and assessment procedures to qualify for disability benefits and allowances (Hanan 2012, Hauben et al. 2012).

Evans (2011) indicates that disabled people's social inclusion and community participation is getting worse because of more difficult access to transport and certain public and social facilities and jeopardizes independent living. It has also been witnessed that social and health services have been more difficult to access since the beginning of the crisis. It has been disturbing to observe that reassessment of disability status with more restrictive criteria's draws the services back towards the medical model of disability (Ibid). Detrimental effects of the economic crisis and cuts in public spending on physical, financial and emotional security of disabled people in the UK have been noticed since recession has been officially recognized in England in 2009 (Gore and Parckar 2009). The study in the UK shows that austerity measures make it more difficult for disabled people to meet ends, access support and healthcare services, put them under the financial strain and lead to difficult decisions when prioritising their needs. The authors of the study highlight that many disabled people had to turn to family and friends for help and assistance or use their own finances to cover their social care needs (Ibid). Philipson (2012) argues that social exclusion becomes an issue when certain systems break down due to the economic crisis. The economic crisis creates challenges when it comes to the standard of living of vulnerable people (Ibid).

According to the latest study conducted in Greece, the country that lacked a rights based approach to disability anyhow and practiced means testing access to services and has been deficient in rational policies, the situation of disabled people has become agonizing and very bleak since austerity measures have been introduced (Marinakou 2012). Despite the growing

demand for social protection reductions in pensions and benefits have been progressive and vulnerable people who have already lived on the poverty line are hit most (Ibid). Besides, disabled people have to wait longer for doctor and hospital appointments that have been extended as long as 3 months and doctors have been restricted to the amount of medicines they are allowed to prescribe daily as well as to prescribing only medication in accordance with their specialisation (Ibid). As indicated by Marinakou (2012), at the time of the research over 60,000 people were waiting for disability assessment as without a disability certificate they are unable to obtain any benefits. This waiting time, since the beginning of the recession, has extended from 2 to 8 months which is detrimental to many disabled people, according to research. The collapse of social services and the closure of some NGO's that would provide the majority of services to disabled people in Greece, put additional emotional and financial strain on families that had to take even more responsibility for the disabled family members. Likewise, decreasing working hours and days, reductions in staff and cuts in salaries shrink whatever services and support were available to disabled people (Ibid). The Greek investigation shows that poorer access to healthcare services, cuts to access to rehabilitation services, increased charges for assistive equipment, cuts and re-examining of disability benefits and any additional charges such as increase in VAT, prices and taxes, rise poverty amongst disabled people, have damaging effects on their living situation, physical and mental health (Ibid).

Recent research carried out by the European Foundation Centre (2012) across the EU countries shows that 1 in 5 disabled people in the EU are in threat of poverty in comparison to non-disabled population due to severe financial measures embedded by the governments. Major negative impacts of the economic crisis and austerity measures on disabled people were recognized by the study and areas affected highlighted. These include closure of services such as day care centres, rehabilitation, home care services and movement towards privatisation of public services. Furthermore, Fenger et al. (2013) argues that in times of the economic crisis disabled people are more prone to be stigmatized as they highly depend on benefits and society is more inclined to perceive them as fraudulent benefit claimants. Ongoing economic crisis has robust, negative consequences on citizens' health as well (Stuckler et al. 2008). Moreover, austerity measures deteriorate living conditions of disabled people and have significant implications for exercising and enjoyment of their human rights. As stated in the report by the UN Human Rights Office of the High Commissioner (2013) governments' obligations to protect human rights, especially of vulnerable and marginalized groups, in times of the economic crisis have become of less importance. Austerity measures cause many severe human consequences and are a risk to rights such as the right to health or adequate standard of living or social security and governments failed their obligations to respect, protect and fulfil the rights of vulnerable citizens in times of economic crisis, in favour of bailing out the banks, and recovering the economy (Holland 2012).



## 5. Theoretical framework

In this section theory of social model of disability and the rights based approach will be explored to present further the justification for the impact of the economic crisis and governmental expenditures on adults with physical impairments. These theories were chosen on the basis how they relate to research questions and will support the final analysis of the research findings.

### 5.1. Social model of disability

Two models of disability, the medical and social models, outline the way disability is recognized. Both medical and social models impacted the way disability is viewed in the modern world. Consequently, both models have had a major influence in establishment of new laws and regulations that emphasise anti-discriminatory approach, inclusion and equality. The Irish government utilizes policies that are based on a mix of medical and social models. During the time of the *Celtic Tiger* new legislation had been introduced and the existing amended to include disabled people. However, the Irish care system is based on domination of medical professions, diagnosis and medication. Disabled people to avail of services and supports granted by legislation and regulations must go through the qualifying assessment process that is distant from the principles of the social model. The key distinctions of medical and social models are as outlined by Oliver (2009)

<i><b>The individual /medical model</b></i>	<i><b>The social model</b></i>
Personal tragedy theory	Social oppression theory
Personal problem	Social problem
Individual treatment	Social action
Medicalization	Self-help
Professional dominance	Individual and collective responsibility
Expertise	Experience
Adjustment	Affirmation
Individual identity	Collective identity
Prejudice	Discrimination
Attitudes	Behaviour
Care	Rights
Control	Choice
Policy	Politics
Individual adaptation	Social change

Source: Oliver, 2009, p. 45

In order to have a better understanding underlying the ethos of the social model of disability it is important to give a further overview of the medical model approach. The medical model of disability, also known as individual, considers disability as an individual problem. It blames a person for his or her misfortune and presents them as dependably on charity. The medicalization of disability generated focus on *the body* by both the individuals and society and viewed disability as a health problem (Oliver and Barnes 2012). This model was commonly accepted and recognized in Western developed countries up to the second half of the 20<sup>th</sup> century (Barnes and Mercer 2010). The medical model features disability as the product of physiological deficiency caused by injury or as a result of a sickness process (Llewellyn and Hogan 2000). The prominence of this model is focus on rehabilitation and cures and portrays disabled people as needy, depressed, sick and powerless. As stated by

Barnes et al. (2010), "the central thrust of the individual model is to cast disability as a personal tragedy where the person with an impairment has a health or social problem that must be prevented, treated or cured" (p. 24). The utilization of this model gave rise to exclusion of disabled people from social and public life and prevented them from employment and education and many aspects of everyday life. The individual model stresses that disabled people ought to alter their lives and fit in to the environment around them. The environment was described as unchangeable and not flexible (Llewellyn et al. 2000). According to Oliver et al. (2012) an important facet of medical model that presents disability as personal tragedy was that disabled people did not fit in what was perceived as *normal*. This model played a significant role in generation of discrimination, segregation, stigmatisation and intolerance within societies. Exclusion of disabled people from employment, disabling social policies and lack of relevant legislation that were the features of medical model, resulted in disabled people poverty, economic dependency and hostility from society. The medical model of disability increased the isolation and exclusion of disabled people as the consequence of their functional limitations while completely disregarding the role of the environment.

Finally, the social model of disability emerged for the first time when UPIAS published the Fundamental Principles of Disability in 1976 as challenge against the medical model (Oliver 2009). UPIAS was established by disabled people, therefore represented their perception and way of thinking in regard to how disability should be defined. However, it was Mike Oliver, a disability campaigner who has a physical impairment himself, who created the name *social model* that views disability as a social problem. This model challenged beliefs that disabled people cannot recognize their own needs or perform in their own interest (Hancock et al. 2000). The social model was also shaped by Marxism and the criticism of capitalism where the repression of disabled people was a product of structural determination (Twigg 2006). The social model initiated the beginning of shifting from the individual *victim blaming* towards looking at society as disabling. According to the social model, it is society that creates obstacles in the environment and that environment limits disabled people from living lives to their fullest potential. Furthermore, the shift of power and authority from medical professionals to disabled people resulted in changes in social and economic policy changes (Humpage 2007).

As indicated by the European Commission (2002) "the social model views disability not as an intrinsic attribute of a person but as a product of the person's social context and environment; these include physical structure, social constructions and beliefs, which lead to discrimination against people with disabilities" (p.21). Therefore, the social model calls for economic, environmental, cultural, structural and legislative changes in order to mainstream disabled peoples' lives. The model pointed out that when using a word *disabled*, barriers and discrimination are coined in society as this word on its own mindlessly disables people.

The belief underlying the social model articulates that disabled people are compelled to dependence due to unsuitable to their needs environment. The social model argues that by promoting independent living and removal of socially, environmentally, culturally and economically created barriers we can change and improve lives of disabled people. This can be achieved, as stressed by Oliver (2009), by spending less money and time for looking for non-existent cures and by dedicating this time to removal of disabling barriers.

The influence of the social model has been immense as it contributed to changes and improvements in governments' legislation that became more friendly and inclusive of disabled people. It has also brought about changes in the way governmental, non-

governmental, charitable and medical institutions that deal with disabled people are run and organised. Many of them started employing disabled people as they are the experts who know best what they need and want, what is practical and works for them in the real world. The social model set off the new era of disability awareness and although this has not been fully or sufficiently achieved in all societies equally, it has changed the way disabled people are viewed by society and portrayed by media. Beside this model has also diverged from disempowerment of disabled people to their empowerment in all areas of everyday life. Disabled people used to live *sheltered* lives; they used to be condemned to their own homes. Nonetheless, inspired by the social model disabled people built up the strength and confidence to leave their homes and reach for the range of opportunities that in the past were only available and accessible to non-disabled people. The social model changed and shaped the way social workers and other professionals are trained and initiated disability equality training and awareness (Oliver 2009).

Despite its many values the social model has divided the public opinion. Some activists perceive it as an impediment to the future disability studies and movement and deem that the major strengths of the social model became its weaknesses (Shakespeare 2006). Some of the social model opponents highlight that the barrier free world is unlikely workable and that disabled people cannot deny that medical issues they deal with, do not limit their everyday lives. Shakespeare (2006) argues that disabled people face many natural barriers and realistically these barriers are not possible for them to overcome. Also it is rather impossible to get rid of residual disadvantages attached to impairment even in the best adapted and accessible world (Ibid). Regardless of its critical aspects certain merits of the social model beyond doubt led to liberation of disabled people, social change, and social inclusion and gave disabled people more civil and economic rights and involved them in decision-making. While it was an important factor in improvements of accessibility to culture, employment, education, buildings and transportation for disabled people, it has also changed from focusing on disabled peoples needs to the importance of their rights, that has been evident in the growth and development of the rights based approach in disability studies and movement.

## **5.2. Rights based approach**

The rights based approach (RBA) is a relatively new and still developing concept (Lawson 2006). The idea emerged as a result of the human rights movement in the second half of the 20<sup>th</sup> century (Rioux and Carbert 2003). The RBA to disability suggests shift from medical/individual to social model of disability (Njelesani et al. 2012). The RBA is shaped by human rights and human rights principles that every human being is acknowledged as a person and a right holder (UNFPA 2010). As indicated by the OHCHR (2006) it is a theoretical framework for the progression of human growth that is normatively funded on international human rights norms and aims at advocacy and protection of human rights. Nonetheless, there is no universally accepted way of defining the RBA (OHCHR 2006, UNFPA 2010). However, the focal point of the RBA is the fulfillment of the rights of vulnerable and marginalized individuals and groups as well as those whose rights have been abused (OHCHR 2006).

The RBA has been broadly recognized as most preeminent practice by disability movements. This approach coined a new holistic perspective and shift from needs to rights. The differences between the two can be best addressed as:

<i>Needs based approach</i>	<i>Rights based approach</i>
Works toward outcome goals	Works toward outcome and process goals
Emphasizes meeting needs	Emphasizes realizing rights
Recognizes needs as valid claims	Recognizes that rights always imply obligations of the state
Meets needs without empowerment	Recognizes that rights can only be realized with empowerment
Accepts charity as the driving motivation for meeting needs	States that charity is insufficient motivation for meeting needs
Focuses on manifestations of problems and immediate causes of problems	Focuses on manifestations of problems and immediate causes of problems
Involves narrow sectoral projects	Involves intersectoral, holistic projects and programmes
Focuses on social context with little emphasis on policy	Focuses on social, economic, cultural, civil and political context, and is policy- oriented

Source: UNFPA, 2010, p. 90

The contrast between needs based approach and RBA points out that needs approach does not involve duties and obligations, whilst RBA always entails duties and obligations of the state (UNFPA 2010). The RBA's goal is to strengthen individuals to strive for participation, equality, inclusion, empowerment, legitimacy, non-discrimination and accountability and transparency (Combat Poverty Agency 2007). The RBA argues the relationship between the right-holders and duty-bearers and emphasizing that duty-bearers are accountable for fulfillment of their obligations towards individuals and groups and take responsibility for their actions (UN 2006, UNFPA 2010). Right-holders are presented as groups and individuals and duty-bearers as governments, public and private healthcare providers and people and institutions that are in power that have commitments toward the right-holders (UNFPA 2010). According to the principles of the RBA, disabled people have rights and the government has obligations concerning fulfillment and safeguarding those rights. The figure below shows the relationship between the right-holders and duty bearers.



Source: UNFPA, 2014, <http://www.unfpa.org/rights/approaches.htm>

The RBA to disability promotes full participation of disabled people in life, involvement in their communities and states that any limitations to it should not be perceived as caused by their disability only but also by society and the environment (Lawson 2006). In view of the above any disabling barriers should be dealt with by governments' policies, legislation and society has obligations to provide what is necessary for disabled people to fulfill their rights (Rioux et al. 2003, Lawson 2006). Rioux et al. (2003 p. 2) stresses that this involves "the provision of supports, services, and aids to enable social, economic integration, self-determination and the enjoyment of legal and social rights." Furthermore, the RBA advocates against anti-discrimination, promotes mainstreaming, removing barriers to accessibility, reform of legal systems and social change, awareness rising, monitoring the impact of rights based laws and policies on disabled people (Lawson 2006). In respect to disabled people Quinn and Degener (2002) state that

The human rights perspective means viewing people with disabilities as subjects and not as objects. It entails moving away from viewing people with disabilities as problems toward viewing them as rights holders. Importantly, it means locating any problems outside the person and especially in the manner by which various economic and social processes accommodate the difference of disability or not as the case may be. The debate about disability rights is therefore connected to a larger debate about the place of difference in society. (p.1)

The use of the RBA in regard to disability is believed to be the best approach since it ensures that individuals and organizations work accordingly to professionally established ethical principles, embraces societal and cultural factors, engages disabled people in decision making, design and delivery of services and supports, enhances the quality and efficiency of services and supports, and highlights the impartiality of human rights regardless of disability (McCurdy 2011). Furthermore, Nolan (2003) indicates that the RBA advocates for disabled people to be in charge of their lives and enforces their right to autonomy and enjoyment of the same economic, social and cultural rights as non-disabled people.

## 6. Methodology

### 6.1. Ethical considerations

According to May (2008) the researcher must adhere to ethical guidelines and make many ethical decisions while carrying out research study in order to respect participants and protect their well being. Decisions made by researcher in the interest of participants, were consistent with conducts of moral behaviour and according to the highest ethical standards. Four ethical principles were borne in mind so as to reduce risks (Gibson and Brown 2009, Gray 2009)

- avoiding harm to participants,
- informed consent,
- respect privacy and confidentiality of informants, and
- avoid the use of deception and ensure professionalism.

From the very start of the research process, participants were made aware and informed about the aim of the research, the way it was going to be carried out and any possible risks involved (Economic and Social Research Council 2010). Preceding this research the letter for the ethical approval of the study had been forwarded to the Irish Wheelchair Association in order to gain access to participants. The ethical approval letter included the information about the researcher, detailed information about the purpose of the study and the interview guide.

The interviews were carried out in the interviewees own home to ensure confidentiality and anonymity and so that participants would feel comfortable within their own surroundings. It is important in qualitative research to adopt “a warm atmosphere and sense of closeness between the interviewer and informant” (Barron 1999, p.40), in order to make the interviewee at ease during the interview. Questions used during the interviews were designed with respect to participants’ dignity as the main concern. Interviewees were informed that participation in the study was voluntary, that they could withdraw from the study at any stage of the research process and that they could refuse to answer any questions (ESRC 2010). According to the Sociological Association of Ireland Ethical Guidelines (1997) “Researcher has responsibility to ensure that welfare of research participants is not adversely affected by their research activities. They should strive to protect the interest of research participants, their sensitivities and privacy, while recognising the difficulty of balancing potentially conflicting concerns” (p. 6). Participants were asked to sign the informed consent form (Appendix 2) which protects both the researcher and the interviewees. The benefit of the informed consent is that interviewees are aware about the character of the study and it gives the researcher protection in case of any concerns (Bryman 2008, Farrimond 2013). The informed consent was accompanied by a letter with explanation and aims of research and researchers background. In order to maintain high ethical standards, as stated in Barron (1999), throughout the interviewing process I tried to remain impartial, as open-minded as possible and keep professional distance with the interviewees.

As this study has been conducted in Ireland I have obliged to adhere to the Irish ethical guidelines and data protection legislation. Data and information collected throughout this research will be stored in accordance with the Irish legislative requirements, Data Protection Act (1998) and Data Protection Act, Amendment (2003), and destroyed after the study is completed. The appropriate measures will be taken to keep collected data securely and in compliance with the requirements of the Sociological Association of Ireland, Ethical Guidelines (1997).

## 6.2. Participants recruitment

It is not feasible to include in the research each member of the interested group so the researcher has to select a part of the population, a sample that is representative (Bryman 2008, Kalof 2008, Grey 2009). Participants were chosen carefully ensuring that they were representative of their population, fitted the research requirements and that there was enough funds available to conduct the study (Kothari 2004).

Ten adults with physical impairments were chosen through purposive non-probability sampling. Purposive sampling is done according to identified *fit for purpose* characteristics and that the chosen sample is applicable to research questions (May 2008, Bryman 2008)). In case of this research it was adults with physical impairments that live in county Kerry. Any person over the age of 18 was classified as an adult for this research. However, two out of ten interviews were not suitable for transcription and analysis because of the interviewees' speech impairment and issues with fatigue which made it difficult for me to understand what have been said.

The initial contact was made with an employee of the IWA who referred to the regional manager of the IWA to obtain the ethical approval. Furthermore, the employee of the IWA contacted on my behalf certain service users before I was given access to them. After the sample was chosen, informed consent forms along with information about the research and researcher were posted to participants so that they could decide whether they wished to participate in this study. All participants chose themselves to be interviewed at the time most suitable to them and in their own homes.

## 6.3. Research design and methods

This section aims to clarify the justification of the design and methods chosen for the research.

After the researcher formulated the research question, the research design consistent with theoretical framework and previous research was chosen. Preceding this choice the researcher looked at the different potential strategies before decided on one. Research design is a structure of the way in which information will be collected, measured and analysed (Bryman 2008, Grey 2009). A qualitative interviewing research method has been chosen for this study. Qualitative studies are rather of subjective than objective nature (Ryan, Coughlan and Cronin 2007). A qualitative interviewing gives the interviewer more chances to look at the problem from the interviewees stand point and look into what respondents view as important to them (Bryman 2008). The emphasis is on understanding the meaning of human experiences and not on quantifiable data. The cross-sectional design has been preferred for this study as it is suitable when working on research that is conducted over relatively short time scale, on more than one case and it gives a picture of the situation at a particular point in time (Denscombe 2007). In a cross-sectional design of qualitative strategy, the study generally is underpinned by an inductive approach where theory is created out of research; therefore qualitative studies often are a theory-generating (Bryman 2008, Ryan et al. 2007).

There are many ways interviews can be conducted. For the purpose of this study semi-structured interviews were chosen as the most suitable method of gathering data. Semi-structured interviews employ methods of both structured and unstructured interviews (May 2008). Semi-structured interviews allow respondents more flexibility and allow elaborating more on their answers as respondents are not restricted to set choice of answers (Bryman



2008, May 2008). At the same time having specified questions gives researcher more probability to collect data relevant to their research questions. Semi-structured interviews also enable the interviewer to obtain explanation on the answers given as it allows probing (May 2008).

Semi-structured interviews are the most commonly used method of data collection in qualitative research. In case of this study it was rather an inexpensive and economical method of data collection, where the respondents were forwarded by post informed consent forms and a cover letter with the explanation of the study. This involved 10 envelopes and 10 stamps at the current price of 60 cents per postage. Additionally, all respondents were contacted by phone in order to arrange for the interviews. As all the interviews took place in one area of the Kerry County and in participants own homes the costs were kept low as there was no extensive driving involved or no need to rent premises where the interviews could be carried out. As it was a rather small scale research it was a rationally low-cost form of gathering data.

Moreover, semi-structured, face to face interviews have been chosen as when researching social world it allows interviewees to share more about their experiences. It is a preferred method of data collection when the researcher looks for more detail and more descriptive information, and allows the researcher for more spontaneity and does not restrict to limited choice of answers. Face to face interviews encourage respondents to *open up* and talk about their experiences (Ryan et al. 2007). However, the disadvantage of this method is that the researcher may influence the way respondents answer questions and unintentionally ask leading questions.

Before I decided how the interview was going to be taken forward and what questions would be asked I familiarised myself with available literature relevant to the research topic. I had also been reading newspapers and followed the news regularly so that I was up to date with the Irish welfare and social system, legislation and the economic situation in Ireland and specifically with the situation of adults with physical impairments. In the process of designing the interview guide and preparing for interviews I followed Kvale's (2008) seven stages of interview investigation. The interview guide (Appendix 1) was based on open-ended questions. Initially two interview guides were going to be prepared. One with the questions for adults with physical impairments and another for the staff who work in organisations that provide services and supports for adults with physical impairments. Nevertheless, after further considerations I decided to interview just adults with physical impairments and look at the problem area from their perspective only. Two standardised questions about age and gender were asked first. Along with main questions, the follow up questions were prepared. While designing the interview guide I tried to adhere to types of interview questions suggested by Kvale (2008) and maintain them short and simple. I also made certain that the language I used was simple and that there was no professional jargon that could be not understandable to respondents. As Ireland is an English speaking country, all interviews were conducted in English.

All interviews were carried out over the period of 2 weeks. I have ensured that the consent form was signed and permission to record the interview was given before any questions were asked and the recorder turned on. The interviews lasted approximately one hour. After the first interview was conducted I have added another question that was asked after the two standardized questions. As stated by Denscombe (2007) qualitative research often has to be adapted and changed as the research progresses. After the first interview I concluded that to make the interview atmosphere friendlier and more relaxed it is more suitable to ask first a question that would give the interviewees opportunity to talk first about something which



they thought was most important to them before jumping into more direct questions. Some questions were also reworded after the first interview to make them clearer. During the interview I tried to follow the interview guide as much as possible and probe only when it was necessary. I tried to keep in mind to pause frequently and not jump to the next question too quickly. That gave interviewees more time to think about the answers and prevented distraction. It was important not to use unnecessary probing or use leading questions that otherwise would influence respondents' answers. However, during the interviews additional questions were asked that emerged instinctively after what the interviewees said. After each interview I made brief notes about how the interviews progressed. It has been noticed that while answering questions interviewees were looking for approval from researcher and confirmation if they answer questions correctly. Nonetheless, I tried to remain unbiased and not get into discussion.

#### **6.4. Limitations**

One has to admit that this small scale research has its limitations. First and foremost, the research has been carried out only in the Kerry area of Ireland. The reason to deliberately concentrate on this area was motivated by the short time scale of the research as well as the accessibility and availability issues. I decided that focusing on one area will give a bigger and better picture of the situation of adults with physical impairments in a more rural Ireland that could be possibly different to for instance those living in Dublin. Moreover, I have limited this research to adults with physical impairments. Thus, other age groups such as children, youth or elderly have been excluded from participation. Adults with impairments other than physical for instance intellectual impairment have been left out of this study as well. The reasoning behind it is that although people with all kind of impairments and of all ages share some features and encounter similar difficulties in their lives, their needs and requirements can be very different and very individual. Therefore, it would be inappropriate to generalize and combine it in one small research. It is also possible that deciding to interview only adults with physical impairments and not representatives of service provider agencies or other relevant bodies, the results of this study give a more subjective and one-sided view of the impact of the crisis on their lives and living conditions.

Furthermore, as I have worked in the past with 3 of the interviewees and they knew me prior to the research, it adds to the limitations of this study. After conducting all interviews I have noticed that those who already knew me were less responsive, more difficult to probe and seemed uncomfortable to answer questions in comparison to those who had never met me before. This was a surprise, as I was expecting them to be more open and honest about their views and experiences on the economic crisis. However, it is possible that they did not want to be perceived as powerless, disempowered and pitiful. Maybe they wanted to present themselves as they are doing well and managing in this difficult for everyone time.

Because all interviews took place in the participants own home, I encountered additional problems during two interviews. The spouses of two participants refused to leave the room where the interviews took place and joined us throughout the duration of the meeting. Despite my requests not to impede the interviews and that I preferred just the chosen participants to answer my questions they interrupted the interviews on a few occasions with their own answers. Since spouses are often the main carers of adults with physical impairments and assist them in all aspects of their lives they believed the problem affects them on an equal basis so they were entitled to contribute to the answers. As mentioned by Farrimond (2013), I had to adjust to this situation to make them comfortable. However, I

consider that the presence of the spouses might have influenced the way the interviewees responded to questions.

## 7. Data analysis and findings

The interviews were transcribed verbatim and collected data was analysed through thematic analysis method. The thematic analysis is one of the most used analysis methods in qualitative research (Bryman 2008). The interviews were carefully read several times to be familiar with their context. When reading and re-reading the transcribed interviews I tried to ask the following questions to understand what the text is about: “what is going on? What are people doing? What is the person saying? What these actions and statements take for granted? How do structure and context serve to support, maintain, impede or change these actions and statements?” (Charmaz 2003, p. 94-95 cited in Gibbs 2007, p. 41-42).

While looking for themes, focus was on searching for repetitions, categories, metaphors and analogies, transitions, similarities and differences, linguistic connectors, missing data and theory related material (Ryan and Bernard 2003 cited in Bryman 2008). The JBI TAP online software for the thematic analysis has been used to organize data. To extract the meaning from the text a three step process according to the JBI TAP was followed. First, the text was coded and entered to the software. Categories were identified and created out of coded text on the basis of similarity and meaning. Eventually, themes were organised and built out of categories to form representations of the data. The software was used to find the relationship between the codes, categories and themes.

Eight out of ten conducted interviews have been used for the analysis. Both males and females were interviewed aged 36 to 65. All adults had physical impairment acquired in adulthood and caused by conditions such as multiple sclerosis, stroke and spinal cord injuries which resulted in permanent limitations or lack of movement in one or both lower and upper limbs. All participants involved in this study are wheelchair users and one can move around with an assistance of a roller/walking aid. The eight participants included 3 males and 5 females and will be referred in this text as *Informants*:

- Informant 1: Unemployed, married, living with the spouse
- Informant 2: Self-employed, married, living with the spouse and four children
- Informant 3: Student, single, three children, living with one child.
- Informant 4: Unemployed, single, living with parents
- Informant 5: Unemployed, married, living with the spouse and two children
- Informant 6: Unemployed, single, living with the sibling
- Informant 7: Unemployed, single, living alone
- Informant 8: In full time employment, married, living with the spouse and two children.

Four major themes are being discussed respectively to answer the research questions. The first section unfolds different sides of impact of the economic crisis on lives and living conditions of adults with physical impairments and discusses it under themes *Financial hardship* and *Issues with services and support*. The second section covers themes such as *Pressure on an adult with physical impairment and family* and *Declining of choice and control* and outlines how adults with physical impairments perceive the crisis and governmental expenditures in terms of their autonomy/independence and the rights based perspective.

## 7.1. Impact on lives and living conditions

### 7.1.1. Financial hardship

Informants were asked questions in relation to their income, allowances, additional costs and expenses to find out how they cope and survive in the present. First, the informants were asked if they could remember a time when they noticed that there was an economic crisis. All informants responded in a way that pointed towards noticeable increases in prices, extra bills imposed by the government as well as reductions and withdrawal of income support and allowances.

On the 7<sup>th</sup> of December I think, I got a letter saying your disability allowance has been stopped. And that was a particular moment that I will never forget. That was horrible. And it is continued to be stopped. They just cut my disability allowance. [...] I was trying to understand why did they take this away. The awful thing about this is, I got the letter saying, your disability allowance has been stopped and you owe us 9600 € that we over paid you. I was just blown apart from this. [...] I think I got the letter around the 7<sup>th</sup> of December and they said from 13<sup>th</sup> of December, that fast. Your disability allowance is no longer being paid. (Informant 2)

The above quote shows how the governments' attitude towards paying benefits to adults with physical impairments changed suddenly, viewing them as a burden to the Irish economy. Likewise, respondents in Marinakou (2012) study referred to change in attitude to how disabled people are portrayed as deceptive disability claimants and cumbersome to governments' monetary policies. The informant 2 expressed her resentment and stressed how uncaringly and inconsiderately it was handled by the government. She illustrated that without any previous notice or warning her income support that was of the lowest possible level, has been ceased, whilst living her without means of financial support. Furthermore, the informant 2 reflected that although both her and her husband are self employed, she works very little due to her health and at the time her husband, whom she described as her main source of income, had not been working at all due to the recession. This informant has 4 sons who are dependent on her and her husband and whom they try to educate which they find very difficult to continue. Oliver et al. (2012) argue that since the beginning of the crisis welfare provision is in serious danger and governments affected by the crisis did not waste any time to severely cut state-provided welfare. This perception is consistent with Marinakou (2012) who argues that because of these changes the majority of disabled people move past the phase of disbelief about the cuts and changes in social protection policies and measures drifting into a stage of anger and hopelessness.

In addition informant 4 highlighted that she was attending a course at FAS<sup>13</sup> (Irish National Training and Employment Authority) which entitled her to an additional payment along with her invalidity pension. As she described, it was a significant contribution to her income for the duration of the course. However, shortly after the economic crisis had begun not only her income was reduced but also she was not entitled to obtain both her invalidity pension and money for attending the FAS course. Similarly, research findings by Pinto and Teixeira (2012), show that as a result of recession the Portuguese government also made reductions in the budget that aims to support vocational training and employment for disabled people. Informants 1 and informant 5 both commented that they noticed a major difference in what they used to be financially entitled to and how difficult it made for them to survive in the present day. Due to financial cuts, the entitlement to income benefits has been tighten,

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<sup>13</sup> A free training course available to unemployed

reductions in disability benefits and pensions introduced as observed in Marinakou (2012) findings. Moreover, informant 5 commented that the changes were introduced rapidly, going from being fairly good, to some being completely removed.

I've moved here in 2007, and that year all benefits went up in the budget and you got the Christmas allowance. That gave you an extra week's money, believe me or not. And then within the next budget everything was cut. So you are looking at 2008 really. Everything just got cut so there was no more Christmas bonus for disabled. (Informant 5)

Informants 3 and 5 indicated that the heating allowance that was distributed every month throughout the year has been stopped. As they spend most of the day in wheelchairs and around their houses, they have a tendency to become very cold which makes the symptoms of their conditions more acute. Apart from this, informants 1 and 5 stressed that their spouses are their main carers and carers' benefits have been reduced which puts an additional burden on their household financial situation. Moreover, informants emphasized that fuel allowance, phone allowance and their electricity units were cut, emphasizing the importance of these to their income. Gore and Parckar (2009) claim that disabled people in recession struggle to meet even basic costs of living and are driven to prioritise the most essential needs that can vary from making a decision to heat the house or pay the electricity bill. The authors also indicated that because of the tightening of the budgets, disabled people do not receive from the state the support they really need. Informants whose main income is from allowances, related in their stories to new bills and charges such as property tax and water charges as well as introduction of prescription charges as detrimental to their budgets. Marinakou (2012) discussed comparable situation where new taxation, increase in VAT and property tax make disabled people to struggle. All informants, apart from informant 8 who is in a full time employment, expressed their view that they find it very difficult to cope and survive on their income. Therefore, it should be noted that if disabled people were in a position to be employed, and have a reasonable income, they in general would be able to provide a sustainable living for themselves (Whelan and Maitre 2010). Informant 1 described his situation as

The realistic thing about the whole thing is, definitely without a shadow of a doubt 90% of the time by Monday you have no more, you have literally nothing left. Now, that's been living completely by a budget, so you have to be very well organised. There are extra pressures because more is going out and less coming in and definitely by Monday, 90% of the time you are without no money till you are paid again on Thursday, you know so it's crazy. (Informant 1)

Besides all informants, except for informant 8, stated that their income whether it is disability allowance or invalidity pension is not sufficient to cover their needs. That includes the needs associated with daily living as well as those brought up by their physical impairment. This statement is in line with Marinakou (2012) that also observed that poverty among disabled people deepens since the beginning of the economic crisis because new social protection measures and policies are not inclusive of vulnerable groups, introduce more cuts in social benefits rather than increase them and do not correspond with their needs.

My income from benefits is not enough. Not now, no. Not since they made the cuts. Before they made the cuts I would also worry about money but we had enough for our standard of living. But since they made the cuts I worry about money all the time. I really do. Like, before if I needed to service my chair, my electric wheelchair I would

ring a bloke down the road and give him 50 € and he would have done it. But now I have to go through the HSE because I can't afford to do that and you don't know when they are going to come obviously. Where if I go down the road it's done but I can't afford to do this anymore. So yes it does affect me and I do worry about money now. I really do. (Informant 5)

When you have to pay for fuel, shopping, ordinary household bills and trying to keep a car running there just isn't enough sometimes to stretch. So yes, that's my financial situation. (Informant 3)

This points out that the state has created material and financial dependency of adults with physical impairments regardless of introducing the social model approach by incorporating for instant legislation. However, the state should have taken more steps in creating better employment opportunities as we can see on example of the informant 8 who is in full time employment, that adults with physical impairments whenever given the opportunity to work and earn their own money are able to survive better with the circumstances of the crisis. One of the social model focuses was to remove the economic barriers but lack of adequate employment opportunities for disabled people created economic dependency on benefits and welfare and failed to remove the economic barriers (Barnes and Mercer 2010), which is particularly visible in the informants' responses. Disabled people unable to work and dependent on benefits are looked upon as per their inability, powerlessness and unproductiveness and are downgraded to the bottom of *social ladder* (Ibid). Another informant stated that low income support, cut backs and additional costs made her rethink and rearrange the way she manages her finances and lives her life.

You just have to cut the corners and cut back. I don't live a highlife so I suppose thank god. Do you know it's not enough what I'm receiving, really there wouldn't be enough really. You have to be more aware of it now, than you used to be before. It's a lot of things we would like to do but you can't. It's tight enough. It affects everyone, particularly everybody with disabilities because things have been cut and you have new bills, you have property tax, water tax coming in and you have to find the way to pay that, so you have to cut something else. (Informant 7)

Informants stated in unison that they have to pay more now for everything, have new expenditures, however, their income remains the same or in case of some have been reduced or completely withdrawn, and they receive less supplementary benefits. They compared what they receive in their disability payments with the outgoings pointing out that they are unable to manage existing payments not to mention the new bills introduced by the government. The unemployed informants indicated that because of their physical impairments they are not capable of having a job so they have no choice other than depending on benefits. All informants stated that disabled accessible workplaces are scarce anyhow and with the economic crisis it is even more difficult for them to obtain employment. Some informants indicated that complexity of their conditions and the scope of their needs severely limit their employment options to practically none. Similarly, Marinakou (2012) points out that in recession disabled people obtain insufficient benefits and social services and experience social exclusion problems that are a result and an outcome of being unable to secure employment due to their condition and lack of facilities and assistance in a workplace. Informants also disapproved of governments' approach to cuts in disability income and allowances declaring that it is a big issue for them as they cannot physically go out to work and earn money to have sufficient budget from week to week. Therefore, they agreed that any extra costs puts a strain on their household budget and their physical and mental health

causing a lot of anxiety as they have to be anxious even more of their spending. This statement is in line with the European Foundation for the Improvement of Living and Working Conditions (2011), which argues that the decline in standard of living in times of the crisis have been noted as well as deterioration of wellbeing as many households find it difficult to cope with paying bills, debts and payments associated with daily living expenses. Due to the economic crisis and changes in public expenditures, social and material conditions of adults with physical impairments deteriorated, the society disables them and drifts to medical, individualised model of *personal tragedy*.

Contradicting this, informant 8 stated that although his salary was cut by about 15% and new bills came in, he has not really been financially affected as his income is high enough to cope with these changes. The same informant highlighted to be very lucky to be able to work and earn money as otherwise he would not be able to cover his expenses. This informant also stated that because he does earn his own money, he does not mind to contribute and cover payments such as charges for prescriptions and medication.

However, informant 4 criticized the government for introducing prescription charges and for handling the situation and not informing people about exemptions to this payment. Correspondingly, Marinakou (2012) study findings show that austerity measures resulted in disabled people having to pay the full cost of medication or care aids in Greece since the beginning of the global economic crisis. Informant 5 expressed similar concern. Moreover, only 2 out of 8 informants were informed that because of their long term illness they are free from paying charges for their prescriptions.

With a recent budget they put up prescriptions to 2.50 € per item that now cost me 20 € a month which didn't cost me anything before obviously. But then talking to someone the other day, she was on a long term illness card which we never heard of. Apparently if you are on a long term illness card you can get your prescription for nothing. If you have a medical card you have a long term sickness and we have now applied for a long term illness card but nobody tells you that. We had to find out for ourselves so if I get that and I get my prescriptions paid that might make a difference. So yea I want that to help towards, because 20 € a month is ridiculous. It always comes very strange. And I don't know why putting it through the back door. Why it wasn't announced? Well I do know why it wasn't announced because they don't want people to be getting it. (Informant 5)

In line with the arguments presented by CWDA (2009), in times of the economic crisis demand for benefits and allowances is growing but regardless of financial struggles the eligibility for income supports and services declines or is delayed and curtailed and leads to poverty and poorer physical and mental health outcomes. The informants, because of their physical impairments heavily rely on transport, whether it is their own adapted car or wheelchair accessible taxis. Informants 1 and 5 expressed resentment that because of growing charges and their income remaining basic, they really struggle to cover costs associated with running of the car for example regular servicing or paying instalments for the loans they obtain for the purchase of adapted vans. Furthermore, similar challenge was expressed by informant 3 and informant 6 who stressed that at the beginning of the crisis the government tried to remove the mobility allowance, which eventually was never passed. They emphasized that this mobility allowance means a lot to them as it pays for taxis when they have to go to hospital for doctors' appointments or other regular activities such as doing grocery shopping or social outings. Oliver et al. (2012) would argue here that decline in governments' considerable spending on disabled people drives them towards the medical model of

disability that goes back to the traditional *personal tragedy* of disability and portrays them as an economic burden. Nevertheless, both informants stated that the mobility allowance as it is, is not adequate and informant 3 stated that “once a month I fill it up and make sure that it lasts for the whole month. But that’s it. That’s what I do with it”. It can be noticed from the informants’ answers that there is a drift to a society controlled by the medical model theory such as charity, vagueness of provision, outcome and *personal tragedy* seems to be the future for disabled people (Oliver et al. 2012).

Over the years the social model became a feature of governments’ plans and practices and welfare agencies (Oliver et al. 2012), still we can see from the informants responses that the trend has been reversed and returns to the *old ways*. Due to changes in governmental spending on income benefits and allowances, adults with physical impairments in Ireland are forced again to adapt to the changes initiated by the environment, as it used to be illustrated by the individual, medical model of disability (Llewellyn and Hogan 2000). In line with this statement informants are incapable of *enjoying* the material and social benefits of present, contemporary living (Barnes and Mercer 2010). The changes to income and support services increase isolation and exclusion and as a result prevent adults with physical impairments from social and public lives and adequate standard of living.

### 7.1.2. Issues with services and supports

In regard to availability, accessibility and quality of services and supports, informants expressed their views that because of their physical impairments they hold medical cards which entitle them to free medical care and medication. Therefore, none of the informants had any issues with GP<sup>14</sup> care and found their first line doctors very accommodating. However, their main concerns were the waiting time that increased since the beginning of the crisis. According to informants’ responses, there are extensive waiting lists to avail of services of specialised doctors and medical procedures that can be done only within the hospital environment. As indicated by informant 4, not all medical and healthcare services are covered by the medical card.

My medical card doesn’t pay for, if I have to go to see my neurologist or urologist. It doesn’t pay for that. So I’m looking at what, specialists visit is about 120 € per visit. And I need to see my neurologist regularly. (Informant 4)

The informant 1 criticized the management of some services stating that although he can gain access to a specialised doctor in his local hospital, that same doctor is unable to take care of his needs due to lack of facilities in the hospital. This forces the informant to travel in order to obtain necessary to his health needs service.

There is a lot of waiting lists for treatment in a way that, I need a neurologist specialist. There is a neurologist specialist in the *hospital X* which would be our hospital but she has only outpatient access, but if you need to go in there she has no beds. She operates private. But I decided not to take this neurologist on board, I kept with the neurologist I had first in *hospital Y* because for a simple reason. When the infections do occur and you need to see neurologist and you need to be admitted there is beds in place. And that’s covered by the medical card. But there is a 2 hour journey there and that’s big, at my own cost again. The neurologist here has no public beds. She has only private beds in a private hospital so why to give her outpatients if she

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<sup>14</sup> General Practitioner



has no beds? That's another cost because I go to *hospital Y* twice a year minimum to be checked out by the neurologist. (Informant 1)

Both informant 1 and informant 4 recognized that they have to pay extra for specialist visits as these are not covered by the medical card. Yet, the medical card will cover hospital care if referred by the specialist doctors. Nevertheless, the informants noticed that waiting lists for public hospital beds are extended which with their conditions, reoccurring infections and urgency for some treatments is intolerable. Due to long waiting time for treatment, if necessary, some informants decided to go with the private health insurance. Similarly, this same challenge was stressed by Marinakou (2012) findings that severe austerity measures extend waiting time for services such as doctors appointments and benefits that are risk to disabled people's health and as a result sometimes they have to pay out of their own pocket to see a doctor or avail of health treatment. Nonetheless, informants who hold private medical health insurance along with their medical card stated that they do it because of fear of being unable to obtain care exactly when they need it. Hanan (2012) argues that many states, since the onset of recession removes or reduces subsidised access to services and consumers are forced to turn into a market economy. Moreover, they stated that this private health insurance secures beds in hospital but will not pay for specialist doctors visits.

I decided to get VHI<sup>15</sup> (private health insurance) and it costs me a lot. VHI wouldn't pay for the neurologist visit. But what it does pay for is, if the HSE had to get me into the hospital, it could take 4 days sitting in A&E<sup>16</sup> on the trolley as there are long queues for beds. And in my situation, thankfully I haven't had reason to go to the HSE to look for a bed, but with the VHI it's kind of case, she needs bed, she is a paying customer so we will get her bed. So for my own piece of mind I just pay it. (Informant 4)

Majority of informants agreed that there were waiting lists to see specialist doctors, treatment and hospital beds prior to the economic crisis, but since the financial crisis the situation has much worsened. As described by informant 6, it is unacceptable for her that not only her physical impairment restrains her but also the way the public healthcare is distributed and the way the healthcare system operates now overall. Lambert (2013) argues that austerity measures should not deprive vulnerable citizens of access to most basic social and health supports and services and should not reverse positive changes in policy development back to the individualised, medical methods. Informant 6 has also expressed genuine distress about how her case was dealt with on one particular occasion and how unaccommodating towards her physical impairments she felt.

Because of my disability, of its progression, I no longer can have a smear test at the doctors. And a year ago I went to my doctor to organise it for me, to inform the hospital. And she did it on numerous occasions. So that's even a doctor's letter, and I've only just been notified that I've got my appointment to see the whoever the name of the person is. So I got my notification finally. So it's nearly taken a year and please god they won't find anything. It made me angry, extremely angry. (Informant 6)

Another informant claimed that it was suggested to him to use private services in order to relieve the symptoms of severe spasms. The services indicated are not available through the medical card. The informant reported that he is not in a position to pay for them despite the improvements this treatment could make to his health. As confirmed by Oliver and Barnes

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<sup>15</sup> The Voluntary Health Insurance Board

<sup>16</sup> Accident and Emergency



(2012), there is a noticeable shift from provision of state welfare towards privatization of services since the onset of recession. This has been stressed as giving customers more choice and control. Ireland has a mixed economy of welfare, thus *buying* welfare and services is not a novelty. However, this is highly disputable as the majority of adults with physical impairments are unable to work because of their condition and there are very limited workplaces that would facilitate the needs of adults with physical impairments; therefore they are not in a position to pay for these services.

Furthermore, both informants that hold private health insurance and those who do not precisely articulated how healthcare becomes more of a marketplace than commodity since the beginning of the economic crisis. They also pinpointed what effects it has on their overall wellbeing. Those who hold VHI stated that the cost of it causes anxiety if they will be able to pay instalments for the insurance each month. Informants who do not hold VHI emphasized how uneasy it makes them and how they dread any infections or need for stay in a hospital because of the waiting time. This is consistent with Marinakou (2012) claim, who similarly noted that health of disabled people worsens as an impact of the crisis which brings constant worrying and anxiety about the health and the future. Other informants drew attention to some care treatments that are not free through the medical card since the beginning of the crisis but of which they must get hold of on regular basis. They mentioned that lack of these services could be a big issue when it comes to their conditions and how they think their needs are misinterpreted when it comes to the governments decisions in regard to adults with physical impairments.

A further important issue mentioned almost by all informants was the waiting time for new equipment and servicing of equipment such as wheelchairs or walking aid. All informants generally declared that this equipment needs to be taken care of and serviced regularly. Thus, waiting 3 months for a wheelchair to be fixed or some parts exchanged was described by one of the informants as unreasonable as this means they cannot leave not only their own homes but sometimes even beds. Moreover, the informants referred to bureaucracy they have to go through these days before they reach any consensus and ensure that their requirements have been met. The informants disapproved of the way they have to deal with the HSE staff that makes decisions, stating that they realised those people are not even fully aware of their conditions and their needs. One informant depicted her situation when she applied for a new wheelchair as the old one was not meeting her needs anymore, yet she was denied a grant that would enable a purchase. Two other informants referred to a situation where after a long waiting time for a new wheelchair, they were delivered equipment not fully kitted out which prevents them from using it. Along the lines of the above responses, Conroy (2010) claims that there is a draw back towards *personal tragedy* that makes disabled people to experience social control and segregation. According to the quotes below, the lack of fully equipped new wheelchairs appears to be a problem and can even be hazardous to adults with physical impairments.

I got an electric wheelchair about 6 months ago and when they brought the chair, there was no cushion with it. So I can't sit in it and use it. Because cushion is the 160-180 € and they didn't budget for it so I have rang them several times since they have to wait until their next quarterly budget [...]and I have to wait until they get money to buy the cushion. (Informant 4)

It is only in a last 6 months that I have actually got another one (wheelchair). I'm supposed to get it a few years back, anyway it arrived and it's bigger and I would use it when I go out for outdoors but I would have liked lights in it when I go out in the

evening. But funding didn't allow for lights, so you are in the dark. The waiting time for it was extended and when I got it, I don't have any lights so if I go out in the dark, it's dangerous so I don't so that's another side of (Informant 7).

The same evidence has been recorded in Greece where the funding for equipment for items such as air cushions have been removed (Marinakou 2012). Another informant described how circumstances when it comes to obtaining new equipment have changed comparing to times prior to the crisis. The claim made by this informant is in line with the argument that government's decisions in public spending and provision of state funded programmes put the problem back from the collective responsibility as emphasized by the social model of disability, towards the individual responsibility (Llewellyn and Hogan 2000). According to research carried out by Marinakou (2012), the economic crisis and austerity measures have harsh impact on the provision of social services. Informant 3 stressed that formerly it was trouble free to acquire whatever equipment she needed to enable her to live relatively normal life.

In September 2012 I went to see a physiotherapist in *hospital X* and she gave me a form to take down to the stores where you collect stuff, disability aids and stuff to collect a new roller walker. And by that stage they stopped giving them out. It was only last week I got a new one. Because they couldn't finance them. Yet, last week my OT<sup>17</sup> came out and with one. So it has taken me from September 2012 to February 2014 to actually get a new roller walker. And it is necessary for me to have it. Yes, I wouldn't go out without, I wouldn't walk outside the house without it. (Informant 3)

When it comes to home help support some informants stated that their hours were remaining the same. However, two informants argued that at the time of cut backs in home help support hours they were very sick and they believe that was the reason they were able to hold on to it. One of the informants mentioned that her home help hours were cut down from 2 hours per day to one hour which in fact means she is left with unfinished or undone jobs around the house. Respectively, Marinakou (2012) remarks that new fiscal policies lead to for example staffing cuts, decrease in hours and days of provision of services and create barriers to access for disabled people. A different informant described how she had to argue her points to keep her home help hours which she found extremely hurtful and unpleasant to deal with. Two informants specified their hours in home help and personal assistance have been reduced, though it was between 15 minutes to 30 minutes which at the present time they are able to cope with. Nevertheless, they stressed that at the moment it is durable and they can accept it.

I can cope with that. But if it had been more then of course it could have been worse. But 30 min it's not too bad. As long as it doesn't get anymore. (Informant 6)

I'm ok with that for the moment. But if it goes beyond certain line then I scream, I make noise. (Informant 8)

All of the informants discussed during the interviews problem with change of culture in service delivery since the commencement of the economic crisis. One informant suggested lack of concern about their daily needs and requirements and highlighted how the public care services informed him without former notification about staff absences for two consecutive weeks due to holiday leave. This informant described it as disgraceful stating that public care services save money at their cost by sending several people on annual leave before the end of

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<sup>17</sup> Occupational therapist

financial year instead of managing it in a way that a disabled person remain receiving their services.

You see if you have 4 or 5 people coming to your house and all of a sudden they tell you, you have a fortnight holidays. Now they quite entitled to that, but from my point of view, that's bad management. If you said all this to HSE, I have no one coming in, they will say, she is entitled to holidays. But I know she is entitled to holidays. But how come 4-5 people are entitled at the same time? You can get over 1 week, but if you have 2 weeks, it's a long time, it's very draining. (Informant 1)

It can be observed from informants' responses that the economic crisis and changes in delivery of services that is crucial to the everyday life of adults with physical impairments, give rise to growing levels of anxiety, isolation, and have negative impact on mental health and well being (Marinakou 2012, Pinto and Teixeira 2012). The informants regret that the government, in order to save the money is cutting corners in the delivery of care. All of the informants objected to unqualified and untrained home care staff taking care of them. The informants claimed that because of the crisis they have been informed that there is no money for the staff to receive adequate training necessary to care for an adult with physical impairment. They expressed a vast concern in regard to their own and the person who care for them safety. As one of the informants described the staff that works with him has no idea how to operate a power chair which he considers as unprofessional and hazardous.

There is a person coming in to put me to bed. That person doesn't even know how to drive that wheelchair up to the bed or take it away from the bed when I'm inside the bed. Now, it's dangerous, because these things are absolutely dangerous like. (Informant 1)

This is consistent with a statement that the expenditure on service provision, staffing and social welfare programmes have been reduced, which is clearly reflected in the quality and quantity of services (NESC 2013). Moreover, one of the informants added that not only the training is not introduced for the staff but also carers are not supplied with items essential for personal care. Lack of use of appropriate personal safety equipment such as for instance rubber gloves can lead to adults with physical impairments obtaining an infection and consequently lead to serious sickness and the need for hospitalization. It has also been mentioned by some participants, how irrational they find some of the decisions made in order to save money. The below citation shows how decisions made without consultation with adults with physical impairments can cause suffering to their health and wellbeing.

There was once time when I had a suprapubic bags<sup>18</sup> on, there was an elastic band that you get in the package, they all came together. And there were 4 or 5 of them, you change as the month go by. Now they reduced that down to 2 bands for a month. And what happens with the straps they put on the bag that you have them for a month or whatever, they get worn and they cut into your leg. And then like you have no feelings in your legs so when your leg is cut then it takes an awful time to heal. And they don't see that like. (Informant 1)

Similar challenge was emphasized by Marinakou (2012) who observed a major fall in health care provision and services as a direct result of the economic crisis that results in insufficient care and medical supplies. Quite a few informants illustrated their dissatisfaction with

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<sup>18</sup> It is a thin tube which is used to drain urine from the bladder. It is inserted into the bladder through a cut in the tummy, a few inches below the navel. (B & BF 2014)

changes introduced in annual entitlement to respite programme and they all described the access to respite as very important to them in terms of participation as well as a break for their families from taking care of them. According to these claims, Oliver et al. (2012) argue that reductions in expenditure, withdrawal and changes of state funding and redistribution without a doubt will sentence many disabled people to loneliness and isolation. Due to reducing the amount of availability of the grant, the majority are not in a position to avail of it any longer.

Furthermore, another informant referred to the loss of her annual subscription to the local swimming pool. The informant described the possibility to go swimming as a vast help in delaying the worsening of her condition. The same frank anxiety was expressed by some of the informants when it comes to the access of physiotherapy. This perception would agree with the thought that disability becomes again just something that is caused by biological deficiencies and not externally imposed by the social arrangements (Shakespeare 2006). The informants agreed that they do not obtain physiotherapy through the public health and social care service provider anymore as it has been stopped. Still certain informants pointed out that they are invited rarely to the hospital for physiotherapy even so it is impossible to obtain any positive health outcomes with this frequency.

My physio has been cut so much you know. In my opinion I should have physio once a week, no questions. And like, once every 6 months now, inside in a hospital it's more for an assessment to make sure that I'm ok, I don't know. I don't even know why. I don't. I should be getting things like stretches and everything, every day. (Informant 4)

The informants' statements prove that the government try to take the responsibility in social policy of their backs by reducing social expenditure in disrespect to vulnerable groups (Oyen, 1986, p.6. in Oliver et al. 2012). The informants implied that since they manage to obtain some physiotherapy through the nongovernmental organisation that provides physiotherapy through contribution of volunteers and fundraising. Nevertheless, this has been described as helpful but by no means sufficient.

My physiotherapy is not through the X anymore. I have it only through the Y and she comes to me once every 3 weeks for an hour to my home. And I would do with getting it more often. Maybe my legs would be more supple whereas right now one of my legs is gone extremely heavy. (Informant 6)

This statement is in line with the Finkelstein's criticism that disability is a creation of social oppression rather than impairment (Thomas 2004). Consequently, Finkelstein (1999) cited in Barnes et al. (2010) argued that fall in dominance of medical and allied professions in decision making, task-oriented and bureaucratic duties when it comes to provision of services to disabled people lead to their empowerment. Yet, it seems Ireland is moving backwards in the direction of bureaucratized, mindless approach that damages the basic aims of the social model. Most of the informants responses would agree with the thoughts of Oliver (2009) who highlights the significance of medical and healing therapies in disabled people's lives and how barriers in a form of creating discriminatory access to health and social support services leads to the distress associated with disabled people lifestyle owing mainly to the lack of medical and therapeutic services.

## 7.2. Perceptions of adults with physical impairments

### 7.2.1. Pressure on an adult with physical impairment and family

Many of the informants felt they were becoming a burden to their families and to themselves because they were unable to take charge of their lives in activities and tasks once supported by public services. All of the interviewed informants depend on the help and assistance of other non-disabled people to varying extents. Thus, do not have full independence and autonomy in their everyday lives and as stated in Barron (1995) independence means handling different activities of daily living with least assistance or exercising power in day to day life. One of the informants referred to the situation while waiting for the decision on the grant to build downstairs accessible toilet and wet room while in the meantime he completely depended on his wife trying to get him upstairs.

My wife helped me get upstairs but she had to try to pull my legs. I don't know how we have done it actually, but we did it. [...] I was worried about my wife bending and lifting me. (Informant 5)

Moreover, some informants highlighted how they feel they become more dependable on their families and how useless and worthless it makes them feel and how they lose slowly their dignity. Another informant expressed her regret that she is unable to do even simple things around the house and although she has plenty of time she depends on her elderly mother. She has also mentioned how she worries about her mother because of her age and her own future stating that she realises her mother will not be able to help her long term. At the same time informant 4 emphasized that with most tasks and activities she requires assistance. However, she pointed out that her own parents are getting old and cannot bend and strain themselves in order to put her into bed or do other tasks. Most of the informants revealed that even though they receive support from home help and personal assistance with personal care, putting into bed and getting up, this does not include weekends or holidays and can be provided on the basis for instance 3 days per week only. Therefore, it is their parents, spouses or siblings that have to take charge of those duties.

The remaining mornings it's all left to my wife. And there are no weekends in that. It's my wife. So in the end of the day my wife is, you know she has to be here 100% with me because they have time off and there is no one put in place when they are off. (Informant 1)

According to this citation there is little concern about what happens with adults with physical impairments during days of carers absences. This perception is in line with the statement by Barron (1995) that if autonomy can be enjoyed, it is determined by whether a person is able to be a part of a social setting, stressing that social setting can either enable or disable persons autonomy in day to day life. From the informants responses we can see that their autonomy in the form of choosing who is going to carry out tasks or to carry out activities without dependence on others is breached. Certain informants stated that they believe it is unjust not only on them but also on their families. As described by one of the informants, their families should not be prisoners of their physical impairment who by no choice must always be on duty. Despite indicating that their families are very good and willing to help, they felt as it is unfair on them and they should not be involved too much in their care. Therefore, Combat Poverty (2007) argues that in line with the RBA every human being should not be stripped off the means necessary to enjoy a satisfactory standard of living and their rights. The informants agreed how much it means to them to be as independent from their families as possible. Several informants reflected that they consider the state to be responsible for

providing the assistance. Informant 3 portrayed a situation when it was suggested to her by public care service providers, that her daughter should take part of the responsibility for her mother's care.

It was all the time, oh your daughter can do this, and your daughter can do that. And my daughter at the end of the discussion we had, my daughter came in to the sitting room and she said she was a student, she was working, she was a normal 18 year old who wanted to enjoy that part of her life and she didn't feel comfortable in respect for me or my daughter to be showering me.[...] putting things on my daughter and expect her to take on such a big responsibility when she was trying to do something so that she could have a good life and a good job when she gets there eventually. (Informant 3)

This informant expressed her resentment how she felt she was putting pressure on her young daughter who tries to educate herself so as to have a reasonable future. The same informant highlighted how inconvenient it makes her feel that the state demands her daughter to care for her. A different informant explained that since losing some of her care assistance hours, she has to wait till someone gets home to assist her to the toilet. As she has only sons, she made the point how she believes it is not appropriate for her to involve her sons in it and that she prefers them not to do it.

I suppose the fact that they are men and you get them to err, I wouldn't do things like that. I suppose there is the feeling that you have no privacy, you have nothing left. (Informant 2)

Accordingly, the informants brought up the issue of being able to live as independent and autonomous lives as possible. This perception is consistent with Jensen (1988) cited in Barron (1995) who describes autonomy as being able to perform simple tasks of everyday life such as eating, socializing and many more. Barron (1995) also stresses that autonomy means that a person should be able to determine their choices themselves. Most of the informants stated that because of the changes in public spending and loss of financial supports and services they have lost the ability to do important to them tasks that significantly boosted their esteem and confidence. They highlighted the importance of being able to do simple things by themselves as this gives them control of their lives and the possibility to choose what they want.

It feels like things just drift away from you. I have this independence thing, I want to do things myself, and then I can't. (Informant 2)

Doing things yourself when you are in my position means an awful lot. So it's just, I do feel, I think it's not like they looked down their noses but it's, you feel like you are inconvenience. You are not, how can I put it, or they will be grand, they are alright, they just sit at home and doing nothing every day. (Informant 3)

Furthermore, informant 4 reflected on her feelings of despair when it comes to compromising and accepting that she cannot do things the way she wishes to. This informant pinpointed how dependable she is and how it affects her autonomy, self-esteem and confidence while putting her parents under pressure as well.

It feels terrible. I don't want to feel I'm always asking for that I'm such a burden or my mother making me dinner every day and you know. If it's not turned the right way I would say but I've realised that maybe I shouldn't be saying that but just eat it and

that's bad because that's not the way I want to be living. I want to be able to make it the way that I want to eat it. (Informant 4)

This is consistent with Conroy (2010) who points out that disabled people have the right to independence and the possibility to choose how they desire to live their lives. As Barnes et al. (2010) remarks, disabled people become more dependent and are forced to make compromises in situations that they would prefer to perform differently. Lack of adequate state provided care provision forces people to return to informal, family care. Society and environment becomes less inclusive of adults with physical impairments, disempowers them and makes them to live oppressed lives and restricts their autonomy and physical independence.

### 7.2.2. Declining of choice and control

Certain informants stated that the economic crisis and governmental public spending, restrain them in a way that they are unable to enjoy life to the fullest of their abilities and do things they like. They described their present circumstances as living in isolation, missing social participation and inclusion. The informants also pointed out to several restrictions and limitations that made them feeling powerless, disappointed and with low expectations from life. Most informants emphasized how they feel they have lost control and have no choice anymore when it comes to how they wish to live.

Social life into it, there is nothing; you haven't got the money to go out. You have all the bills to pay. So it's hard, it's hard. [...] There is not much you can do in a wheelchair but the bit of the ability you have to get out and do things, you just can't do it. You are totally confined inside. You just can't go and do anything like. [...] Because in the end of the day it's you that's sitting there, it's you that's looking out the window and it's you trying to put every hour down, every day to keep your mind occupied which you can't because you are not able to do things you would like to do. (Informant 1)

The above quote shows how as a result of the economic crisis adults with physical impairments are limited even more in their choices and capacity to participation and inclusion. Along with restrictions that come with being dependent on the wheelchair, other constraints such as lack of funds stands in their way to social connectivity. Indeed it can be argued that as emphasized by Williams-Findlay (2011), austerity measures create a less inclusive society and take control over disabled peoples lives and exclude them from mainstream social activities. Moreover, the informants mentioned the significance of social participation and integration to their mental health and overall well being. Many of the informants revealed how they believe the country's economic situation isolates them more and makes them *prisoners in their own homes*.

We don't socialise much now. Not that we did anyhow. [...] You don't go out because you can't afford to socialise. I think it's important for everyone to go out. Trying to get out once in a while, to not being stuck in four walls of the house. We might go out once every three months now. And before maybe we could go out once a month. With the cuts you just can't afford it. Which is wrong you know. We should be able to get out. You get *cabin fever* sometimes you just need to go out. You sit here every night; there is nothing in the telly. Yea I become mental then as well as disabled (laugh). (Informant 5)

It has been noticed that social connectivity of adults with physical impairments has worsened not only because they cannot afford to go out but also because everyone around is struggling financially. One of the informants claimed that nobody has time for nobody anymore. His non-disabled friends find it difficult to keep in touch with him as they are fighting for themselves to cope financially and to take pressures of their own families. Therefore, adults with physical impairments are left at home with their own company or with their families. It is apparent that there is more isolation coming in and crippling in all the time since the beginning of the crisis. It can be seen from the informants' responses that, as argued by Conroy (2010), many disabled people continue to live in disabling societies that limit their chances to live a self-determined lives and create social and economic barriers that prevent them from a full citizenship.

Certain informants referred to how the present situation lowered their expectations and how resigned they feel. They mentioned that they feel so powerless that they do not try to defend their own and other adults with physical impairments rights anymore. One of the informants stated that after some of her assistance hours have been taken away she did not bother to enquire why or try to get them back. Therefore, it shows her resignation when it comes to dealing with public service representatives in times of the crisis. Another informant mentioned her frustration and feelings of hopelessness and how she stopped challenging the government as it started affecting her health as the stress of waiting, and wondering whether they would cut benefits and so on resulted in her disability getting worse.

I didn't even try to argue with them about my hours. Because I just got to the stage that, you get sick of fighting bureaucracy. Sometimes when I'm well enough I take them on. (Informant 3)

I so got used to living the life that I'm living now, I couldn't even think what's out there that I could do. So that's what you have to live with. Unfortunately you don't have a choice because the government talk for you. (Informant 6)

Majority of informants agreed that the cut backs in income supports and services make them live more sheltered lives. They expressed their desire to be able to do things they like and enjoy, to be part of their communities. These statements were emphasized by many emotional responses such as resentment, irritation and anger that demonstrate their despair with living in the present.

You just can't go out and do the things you would be able to do. Which were not very big things but meant big things to me like going to sports matches and do a little bit of fishing and you know, you're watching everything now. You're watching the petrol, you know and things and its holding you back. The system today is totally holding you back all the time. [...] then when you are at home you are totally confined to the house unless there is somewhere you know that you can afford to go to these places. (Informant 1)

This statement is in line with arguments presented by Combat Poverty (2007) that argues that the RBA means that there should be proportionate division of power and resources and that the RBA optimizes the active, free and purposeful participation in the community. Still the above quote shows a deficiency in being able to exercise participation. Moreover, the informants referred to gradual loss of control and dignity. One of the informants particularly stressed how demoralized and under control he feels and how the meaning of having influence over his life is slipping further and further away.



If you sit in a wheelchair from 9 in the morning till 7.30 in the evening and then a stranger comes in to put you to bed and another stranger coming tomorrow morning to get you up and shower you. Your dignity is gone and at times they are controlling. People in wheelchairs we have no say, I have no say. What they are doing, they are not doing that for me. (Informant 1)

The informant 1 claims that due to the economic crisis, governments' actions destroy the lives of adults with physical impairments. All of the informants pointed out that the government makes decisions regarding reductions and withdrawal of benefits, allowances and services without the consultation with adults with physical impairments. The governments' decisions are completely irrational as they drag adults with physical impairments into further poverty and isolation. Interestingly enough, Holland (2012) stresses that the voices of vulnerable and marginalised citizens have not been heard when the Irish government started introducing austerity measures and that they should not suffer as they had little impact on creating the crisis. It has been stressed by many informants that the government controls their lives and does not include them in decision making any longer. Certain literature suggest that the basic principle of the RBA to disability is that those who represent disabled people should be accountable to them and controlled by disabled people as they represent their interests (Lawson 2006). Informants agreed that they experience more disregard for their specific needs and are left to themselves to sort out how to survive from week to week.

They definitely do not think of the person in the chair. The voice of the person in the chair is diminishing every day. There is silent crying now and it's very frustrating. I want them to hear my voice and my side of it. [...] They don't know no better but for the person in the wheelchair knows it and he knows it 100%. But I think what's happened there, they don't even focus on the individual needs of the person. Because my needs are different from your needs or other people needs. So they are not introduced. [...] You are just another page in the book and that's it. And it's frustrating, really is like. But it's like you always have a smile on your face to everybody that comes in but then at the end of the day it affects your own feelings 100%. No one sees behind the closed doors, the way you really put down your day. (Informant 1)

The above statement shows that the government, which according to the RBA is a duty bearer, does not fulfil its obligations towards people with physical impairments - right holders. This argument is consistent with CESR (2009) that in correspondence with the RBA governments have responsibilities to act in interest of their citizens and protect their rights to survival and a life with dignity and that government's role is to act as supporter of citizens' human rights. However, so far the government response to the crisis is neglect and overlooking those rights. Similarly Rioux and Carbert (2003) claim that according to the RBA governments should take adequate steps to ensure inclusive societies and that disabled people are entitled to avail of all of their human rights.

One of the informants brought up during the interview issues with delivery of services and how he felt powerless when it comes to discuss it with the public care services. The same informant illustrated the lack of collaboration of the public care services with adults with physical impairments to provide a tailored to his needs service. It was pointed out as well that fear of losing a service or being a subject to reduction, prevents him from standing up for himself.

I often say it to my wife like, it's 8.15 pm, I am so tired, now she will say you got to wait until they come in. But I would say why I have to wait. They should be in here, do you know. And it's very, very hard now to negotiate anything with the HSE anymore because they will cut you off, well you have somebody and you just stay on but the situation never is discussed. Fatigue follows the illness, what is wrong with the person is never discussed. I mean, I actually really believe that not for 1 minute, whoever is inside an office, at the other side of the phone, does even realise the age I am and the needs I have and the nature of my disability. Now, they know I am in a wheelchair, that's it. But fatigue is a very big thing with MS<sup>19</sup> and it is a big issue and I literally am falling off the wheelchair. (Informant 1)

The importance of having choice and control seemed to be a prevailing argument in all interviews. Oliver et al. (2012) highlighted that implementation of the RBA to disability has been empowering and gave disabled people a great amount of control and choice. However, the informants explicitly expressed their regret how they feel that the country has let them down. That nobody cares for them or listens to them. One of the informants stated they do not choose to have physical impairments thus should not be treated like third class citizens. The informants declared that they just want to be treated like non-disabled people. This perception corresponds with Lawson (2006) who emphasizes that the RBA promotes equality between disabled and non-disabled people and calls for treating them as equally valued. They do not want to be targeted all the time but be treated with the same dignity as non-disabled people. They described their situation as disappointing and as *a mental torture* as not only they are disabled by their physical impairments, unable actually to go out to work every day but also denied to enjoy the simplicities of everyday life.

I even said to my wife this morning, do you know, my wife puts me into the shower, and I come out and sit in the wheelchair and how they say it, I am spotless from head to toe, but deep down inside, it's like that you are so sore inside. You look so clean from the outside but inside you are really, really dirt. And you get them feelings across to able bodied people, I think they would say you know, oh my god you are lucky that you can go back to road in a wheelchair, and I look at that, if I'm lucky, how lucky are they? (Informant 1)

The above citation illustrates disability as *personal tragedy* as in the medical model and disabled people praised for their *exceptional courage* (Barnes and Mercer 2010), which is opposed to the principles of the RBA. As said by Barnes et al. (2010), disabled people challenge society to include them, to hear their voices, to recognize them as part of society and do not portray them as the "second class citizens and put away out of sight and mind". The social model leads to disabled people regaining the authority and power over their lives in terms of social and economic participation and integration and promotes RBA to disability (Humpage 2007). Nonetheless, the power and authority of the government polices, medical and other professions makes disabled people lose their strength and confidence (Ibid), lose their autonomy and deprive them of choice, control over how they aspire to live their lives. In addition CESR (2009) believes that the economic crisis threatens social and economic rights and human dignity and that in this *austerity measures war* they slowly lose the battle against maintaining control over their lives. Furthermore, Tulkens (2013) suggests a challenge that in times of the economic crisis safeguarding human rights is not an indulgence but a fundamental necessity.

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<sup>19</sup> Multiple Sclerosis

## 8. Conclusion

The aim of this research was to investigate the impact of the economic crisis and governmental expenditures on adults with physical impairments in Co. Kerry, Ireland. In order to answer this question two complementary sub questions were examined. That is how cut backs in public spending affect lives and living conditions of adults with physical impairments and how adults with physical impairments perceive these reductions in terms of their autonomy/ independence and the rights based perspective. The study findings reveal that reductions in public spending on social protection, public services and additional costs and expenses that were imposed as the consequence of the crisis, are resulting in a worsening of the standard of living of adults with physical impairments, affects their health and wellbeing, social and family life as well as diminish their autonomy, independence and deprives of choice and control over their lives.

The theoretical framework of social model of disability has been adapted in this research study to analyze the effects of the crisis on lives and living conditions of adults' with physical impairments. This study demonstrated that social and political decisions made by the government since the beginning of the economic crisis have a grim effect on adults with physical impairments in Co. Kerry, Ireland. It has been argued here, that the crisis driven changes increase financial insecurity and there is growing tension as people struggle in the present day. Adults with physical impairments are more likely to be unemployed as a result of their physical impairment and find it hard to meet the basic costs of living, in times of crisis. The reductions in spending on welfare and social services seem to contradict with the government's policies that aim at mainstreaming the lives of disabled people, promoting choice, dignity and independence. Therefore, undermine the principles of the social model approach that is based on foundations of human dignity.

This backsliding from the social model towards the medical model approach appears to be a growing *trend* when it comes to handling the crisis so as to generate revenue and save the Irish economy. Change on disability issues is a consequence of the severe austerity measures and points out at many challenges that face adults with physical impairments. Adults with physical impairments are prevented from being able to live *optimistic lives* and forced to live *piteous lives*. Unable to avail of certain medical and therapeutic treatments that have been cut down or removed since the beginning of the crisis many adults with physical impairments are forced to turn into the market economy and *buy* their health. However, this proves to be a *luxury* as the informants in this study agreed that on their present income they find it difficult to afford services and treatments that are so necessary to their well being but no longer provided by the state. It is clear from this study that reduced spending undermines adults with physical impairments health needs and alleviates poverty. Retrogressive measures changed governments' priorities and put the importance of the economic recovery ahead of social and economic needs of adults with physical impairments.

It has been mentioned in this study that there are links between reduced spending on social services and poor standard of care provision such as a lack of training for the public services staff and shortage of equipment and tools necessary for use within the personal care. This highlighted how potentially damaging it could be to adults with physical impairments health. Adults with physical impairments need help with everyday activities. However, the informants' responses emphasized that insufficient funding lead to changes in eligibility criteria for home help and personal assistance, therefore putting more pressure on adults with physical impairments and their families. Even though, the majority of informants managed to

keep a greater amount of allocated hours to them, they all expressed concern regarding losing more hours in the future.

The theoretical standpoint of the rights based approach has been implied in this study to analyse adults with physical impairments perceptions in regard to autonomy and independence in times of crisis. As can be noted from the research findings, the informants reported that their autonomy and physical independence gradually erodes. Due to the loss of support measures, adults with physical impairments become more dependent as a consequence of social and economic restrictions and limitations that become more apparent since the onset of the crisis. This is particularly damaging to their human dignity and personal worth. Another issue that emerges here is raising dependence on family members which shows a shift to informal family care provision that is more in line with medical model of disability. Therefore, it is not hard to argue that changes in thinking from the rights based approach towards needs approach can be observed. The informants' responses show that they are no longer in charge and have no control or options to make choices. This lack of freedom of choice and control deprives them of autonomy and independence and does not lead to self determination of adults with physical impairments. The government policies neglect their basic needs to live dignified and independent lives and instead outline how they ought to live.

The findings of this study suggest that without adequate support measures adults with physical impairments are unable to be an integral part of their communities on the basis of equal citizenship. They seem to have less choice and control how to organize their lives so as to be able to live ordinary lives. The informants described a lack of understanding of their situation and how decreasing social welfare supports greatly affect their autonomy and independence. Poorer social participation is cause for concern as it prevents the informants from inclusion, full and active participation in Irish society and forces them to accept the disabling conditions of their environment.

This study also shows that the voice of adults with physical impairments is declining and that they have not been engaged in the decision making process in regard to austerity measures. As per the RBA concept they should have been involved in open discussions with the government so as to present their social and economic priorities and secure a better outcome in the crisis. It can be seen from the findings of this study that the Irish government forgot that as outlined by the RBA, they have obligations towards adults with physical impairments. The government failed in its obligations as a duty bearer towards adults with physical impairments, rights holders by introducing harsh austerity measures that could have potentially damaging effects in the long run. These measures were not inevitable and the government could have dealt with it more inclusively of adults with physical impairments and instead of further impoverishment, they should have supported them and their families to ensure a respectable future, participation, inclusion and autonomy. The findings of this qualitative study also impose the question if governments look after their vulnerable and marginalized citizens and protect their human rights only in times of financial prosperity and security, but neglect in times of financial hardship.

Adults with physical impairments experiences during the recession present a critical overview of the impact of the economic crisis and governmental expenditures on their lives. This presents a challenge going forward and imposes a question, how much further the government will go creating a *loop* system of poverty and exclusion amongst adults with physical impairments. Even though, these study findings highlighted many interesting issues, another line of research worth pursuing further could be to have a broader look at how adults with physical impairments have been affected by the crisis in terms of their legal and human

rights. It has been evident during the interviews that infringement of these rights since the onset of the crisis becomes more of an issue. Due to time restraint and the scale of this study, it has been carried out only in Co. Kerry. However, it would have been interesting to assess the situation of adults with physical impairments in other parts of Ireland, as well as adults with impairments other than physical. The informants who took part in this study live in their own homes, either with family members or independently. Therefore, adults with physical impairments that live in supported accommodation or institutions for adults with physical impairments viewpoints are unknown. Living in one's own home or in institution can present a different picture of the economic crisis and the effects of austerity measures.

Moreover, only adults have been interviewed for the purpose of this research. Thus, younger people, children and elderly did not get opportunity to express their view. Children attend schools and need care of an adult person. Therefore, it involves more support systems and services so it could be interesting to find out if the crisis brought any significant changes to lives of children with physical impairments. The same could be referred to elderly, who are more likely to live on their own or in residential homes for the elderly and have more complex health and care needs because of their age. Furthermore, all participants in this study obtain health, social and welfare services and supports from the same institutions and organisations in Co. Kerry; for instance from the same hospital or the same doctors. Therefore, it would have been interesting to find out how adults with physical impairments in other geographic locations of Ireland experience the outcomes of recession. Their experiences could be very different depending whether the changes have been introduced across Ireland on the same bases as in Kerry. Hence, it would be worth to compare whether their access to services and supports have been impacted and if it has had any economic and psychosocial consequences on their lives.

During the literature review process it became apparent that there is a need for research to focus more on how the economic crisis affects disabled people in terms of their needs and rights and that the most recent research is of more quantitative nature. Further indicators for the future would be that more qualitative research needs to be conducted to look at the impact of the crisis from the disabled people's perspective and how it affects their everyday lives. A lot of recent and ongoing research focuses on disabled people and vulnerable groups overall. However, it could be valuable to get an overview of how the economic crisis affects certain age groups, as children, youth, adults and elderly have different needs and requirements at certain stages of their lives. The indications for the future would be to ensure that when the states' finances are running low, instead of targeting adults with physical impairments and putting into place discriminatory practices, ensure that social and welfare provisions are available and inclusive of adults with physical impairments.

Furthermore, the government needs to be fully accountable to adults with physical impairments for their actions and carry out their duties in a way that empowers them and ensures inclusion and participation in mainstream society. A further suggestion would be to guarantee that human rights of marginalised and vulnerable individuals and groups are at the centre of governments' future social and political developments. Ireland has exited a bail out in December 2013 but it is predictable that cut backs and reductions in welfare and social services will continue to grow. The effects of fiscal policies will influence lives of adults with physical impairments in many more years to come and could be even more visible over the coming years. Tightening of public services will resume having a deteriorative impact on adults with physical impairments. Budgetary allocation that are supposed to result in generating more revenue for the state could have retrogressive outcomes and lead to even more dependency of adults with physical impairments in both social and economic terms and

more reliance on public welfare services. Indeed it can be argued, that this will deepen the poverty and lead to a discriminatory attitude towards adults with physical impairments who already are perceived as less productive and social welfare claimants.

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# Appendices

## Appendix 1

### INTERVIEW GUIDE

1. Gender
2. Age
3. Can you tell me when you noticed/realised that the economic crisis has began?
4. Could you describe your living arrangements?
  - Do you live on your own?
  - Is your house/apartment accessible?
  - Do you live in urban or rural area?
  - Do you require transport to move around?
  - Can you tell me what would enhance your living arrangements?
5. Are you employed?
  - If no: why and how does it affect your economic situation?
  - If yes: where do you work? How many hours per week? Has there been any change to your work pattern since the beginning of the economic crisis?
  - If no: Would you like to be employed?
6. What is your main source of income?
  - Has it been affected in any way since the beginning of the crisis?
  - If yes: can you tell me more about it?
  - Can you tell me how your current income corresponds with your requirements and expenditures?
  - Is it sufficient to cover your needs?
7. Do you receive any allowances?
  - If yes: what type of benefits
  - If no: why not?
  - Have they been subject to cuts or have you been denied any allowances since the beginning of the crisis?
  - Would additional government expenditure improve your living situation?
8. Have you applied for any grants since the beginning of the crisis?? E.g. home adaptation grant, assistive equipment aids.
  - Have you been refused any grants or received less than expected?
    - ◆ If yes: Why? How did you go about it?
  - Can you expand a little on this?
  - What difficulties do you face?
9. Do you require the assistance of care workers and personal assistants with everyday activities?
  - How often and how many hours per week?
  - For what type of activities do you require assistance?

- Have the hours of assistance been subject to cuts since the beginning of the crisis??
  - If yes: how do you feel about it?
  - What are your needs regarding the assistance and care?
  - Are you satisfied with the level of care and assistance you receive?
10. Could you describe your access to healthcare, treatment, medication and prescriptions since the beginning of the crisis?
- Can you tell me more about it?
  - Can you give me some examples?
  - What difficulties do you face?
11. How would you describe your access to physiotherapy and physical activity?
- Can you tell me more about this?
  - Can you tell me about your needs regarding physio?
  - Is your physio subsidised?
  - What are the main benefits you experience from physio?
12. Has your participation in social and community activities changed since the beginning of the crisis?
- How often do you socialise?
  - Do you socialise in a public venue or at home?
  - Why not?
  - What are your expectations and needs in relation to social participation?
13. Do you use any private services/agencies e.g. doctors or therapeutic treatments, and pay out of your pocket for services?
- Why? Can you tell me more about it?
  - How do you feel about it?
14. Do you receive help from family and friends with assistance with daily activities?
- Why?
  - Can you tell me more about it?
  - How do you feel about it?
15. Could you tell me how your autonomy and independence has been affected by the economic downturn?
- What difficulties do you face?
  - How do you feel about it?
16. Do you want to add anything else? Do you have any other thoughts about the economic crisis and governmental expenditures?

## Appendix 2

### Consent Form

You are invited to take part in a research carried out by Magdalena Skalecka, student at International Master's in Social Work and Human Rights, University of Gothenburg, Sweden. The research aim is to investigate the impact of the economic crisis and governmental expenditures on adults with physical impairments in Co. Kerry.

In order to ensure that this project meets with ethical requirements I guarantee to adhere to the following principles:

- You will be given the information about the purpose of the research.
- You have the right to decide whether you wish or not to participate in this study.
- The interview will be conducted confidentially.
- The interview will be recorded as it is easier for me to document what is said during the interview.
- The collected data will be stored securely and destroyed after research project is completed.
- After the interview has been conducted you have a right to decide whether the data can be used for research or not.
- Participation in this study is voluntary. You have the right to decline answering any questions and you are free to withdraw from research at any time.

You are welcome to contact me or my supervisor in case you have any questions.

Student:

Magdalena Skalecka

0879262429

skalcia@yahoo.com

Supervisor:

Professor Karin Barron

Karin.Barron@socwork.gu.se

- I agree to participate in the research
- I agree to be recorded for the purpose of this interview

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Signature

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Date